USING UBIQUITOUS COMMUNICATION TECHNOLOGY TO IMPROVE PEDIATRIC ASTHMA MANAGEMENT

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USING UBIQUITOUS COMMUNICATION TECHNOLOGY TO IMPROVE PEDIATRIC ASTHMA MANAGEMENT

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To my Julie (Seung-Hee), Jayden (Jae-In)

and all of my families.

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SUMMARY

Information and communication technologies (ICTs) for chronic care are increasingly being researched in Human-Computer Interaction [158]. For example, one of the current health management areas where ICTs have been employed is in supporting communications between patients and physicians [140]. This is particularly relevant for patients suffering from chronic diseases since there is evidence that better communication leads to better health outcomes [85].

HCI researchers are investigating different chronic diseases to design and test technology interventions to promote better chronic disease care [88, 102, 103, 137]. However, few have investigated asthma as a case study for designing communication technologies. The World Health Organization (WHO) estimated in 2008 that 300 million people suffer from asthma, and that asthma is the most common chronic illness among children [159]. Asthma affects an estimated 5.6 million children under the age of 18 in the United States. Although increases in asthma prevalence have slowed since the mid-1990s, asthma prevalence remains at high levels [2]. Asthma interferes with breathing by preventing airflow into the lungs. It is difficult to determine the actual cause of asthma and to predict who will have asthma. These unique challenges provide opportunities to investigate pediatric asthma management.

I conducted a series of studies with pediatric asthma patients, families, and healthcare providers to better understand their needs, challenges and strategies regarding the use of technologies. I have conducted interviews, a focus group, and a technology probe study to create and refine initial technology designs for children with asthma and their caregivers. Based on the Health Belief Model (HBM), patient-provider

communications, and my findings in the prior studies, I designed a mobile and web service to increase asthma knowledge and management awareness in the child for better health outcomes, and to affect the perceived quality of interaction with health-care providers. I conducted the initial field deployment with twenty-three patients and eight physicians to learn how the system affected their practices and health outcomes. Based on the result of the first deployment, I changed the conditions of the first study and conducted a second hypothesis-driven field deployment. My contributions come from an increased understanding in three areas: physician-patient communication via a mobile and web services; ubiquitous communication technology designs to improve current pediatric asthma practices; and controlled evaluation of a ubiquitous communication technology, SMS, in the field.

CHAPTER I

INTRODUCTION AND MOTIVATION

Asthma is a complex disorder characterized by variable and recurring symptoms. Asthma interferes with breathing by preventing air from flowing freely into the lungs. The World Health Organization (WHO) estimated in 2008 that 300 million people suffer from asthma, and that asthma is the most common chronic illness among children [159]. It is a leading chronic illness among children in the United States; 5.6 million school-aged children and youth (5–17 years old) were reported to have asthma in 2007 [5]. It is a heterogeneous disease with triggers that differ between patients. Triggers cause attacks when children with asthma are exposed to stimuli in the environment, such as house dust mites and tobacco smoke. The reciprocal action between children with asthma and environmental exposure affects asthma. While there seems to be a genetic component, the definitive causes of asthma have not been established [113].

Asthma management has challenges in three ways. First, the severity of asthma depends on not only the patient's lifestyle, but also on other triggers that he or she cannot directly control. Second, there is no established direct measurement of an asthma patient's status. Additionally, pediatric chronic disease management involves various stakeholders, including children with asthma, caregivers, and healthcare providers (Figure 1).

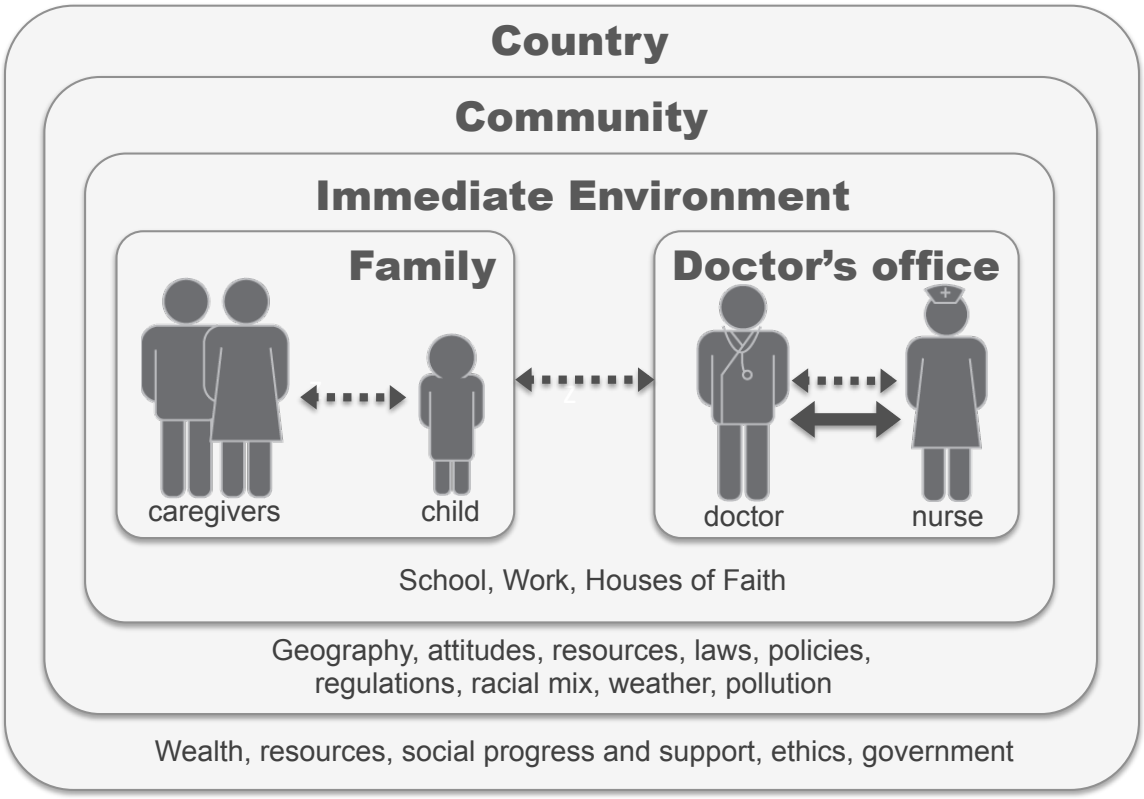


Figure 1: Relationships between different stakeholders for pediatric asthma management in socio-physiological-cultural environment [63].

Interventions aimed at modifying the risk factors for asthma have determined that a multipronged and individually customized approach can improve treatment outcomes [157]. Use of an asthma counselor or case manager to deliver the intervention has emerged as a key component to implementing and delivering secondary asthma prevention measures. Their roles are to identify disease at the right timing and provide intervention to control disease and reduce disablity [114]. Programs, which improve care, educate, limit the exposure of children to allergens and irritants, and reduce exacerbation of symptoms, reduce medical costs related to asthma. However, not every family with asthmatic children is able to access these programs because they are a limited resource.

Ubiquitous communication technology is particularly well positioned to present a viable solution to the shortage of this limited resource. For instance, Intille et al.

studied two trends towards ubiquitous health care management [69]. The first trend depicts an environment with a wide deployment of computing devices to increase the communication capabilities of health information. Patients and caregivers can use computing devices anywhere and, thus, have the potential to send or receive health information anytime. The second trend is a real-time context aware computing platform. A context-aware system can automatically infer what situation a person is in so that it can deliver just in time health advice. These trends may enable technology to raise awareness and motivate management of asthma by providing contextual information to users. In particular, the relevant context includes the observed behaviors, the consequences of these behaviors, and the points of decision that trigger particular behaviors.

There are several known factors that influence effective management of a chronic condition including: open communication between patient and health care providers [22, 24]; a patient's awareness of symptoms and knowledge of her/his condition [130]; and level of adherence to medical regiments [148]. Effective communication may prove as beneficial as proper medication choice in the long-term success of asthma control [22]. Medical care for pediatric patients that have moderate to severe asthma includes regular visits to their pulmonologist (every 3 to 4 months). Despite the knowledge that communication is vital, there is often no communication between the patient and physician between these visits, unless there has been an episode that has landed the child in the emergency room [45]. Thus, pediatric asthma care makes an intriguing case study for the use of ubiquitous computing technology to facilitate communication because it shares some features with other chronic diseases but also presents a number of unique challenges.

1.1 Thesis Statement, Research Questions and Contributions

My fieldwork and experiments have grounded my understanding of what the requirements are for pediatric asthma management and how ubiquitous communication technologies might improve asthma management for pediatric asthma patients and healthcare providers.

I propose the following thesis statement: *Ubiquitous communication technology promoting communication between a pediatric asthma patient and a healthcare provider enhance the patient's knowledge and awareness, resulting in improved health outcomes, patient's knowledge and awareness, and the quality of interaction with the healthcare provider.*

I explored the following research questions to deepen the understanding of how ubiquitous communication technology impacts pediatric asthma patients and their healthcare providers:

RQ 1. *How do pediatric asthma patients, caregivers, and healthcare providers currently use technologies to manage pediatric asthma in their own settings?*

Through in-depth interviews, surveys and observations of pediatric asthma patients, caregivers, and healthcare providers, I contribute to the overall understanding of asthma management practices currently in use and of the needs and challenges relating to the use of technologies. I generated specific design recommendations to guide future work in this area. I explored three stakeholders: pediatric asthma patients, caregivers, and healthcare providers.

RQ 2. *Which characteristics of ubiquitous communication technology contributes to effective interventions for pediatric asthma management for children with asthma and their caregivers in a home setting, and how can we design them to improve pediatric asthma management?*

I used technology probes to explore the problem and solution space of designing for pediatric asthma management, and link the findings to the characteristics of technology probes. I contribute a documented description of my process to inform future technology designers and developers in this field. I explored two stakeholders: pediatric asthma patients and caregivers.

RQ 3. *How do pediatric asthma patients and healthcare providers adopt a mobile and web service over the course of several months to improve asthma knowledge and awareness, and to affect the perceived quality of interaction with the healthcare providers, which can lead to improved quality of life and health outcomes?*

RQ 4. *What is the impact of socioeconomic status, as an independent factor influencing quality of life, on the effectiveness of a mobile and web service? How does that impact differ for improvements in quality of life and health outcomes between patients with public insurance and patients with private insurance?*

To address the last two research questions, I implemented a system for supporting communication between pediatric patients and their healthcare providers. The system was leveraging text messaging with children and a web interface called the Physician's Dashboard to support pediatric patient–physician communication. A deployment of this system served as a proof-of-concept, increased understanding of how patients and physicians adopt new interventions. The studies provided specific evidence of technology impacts on quality of life and health outcomes. I explored two stakeholders: pediatric asthma patients, primary caregivers, and healthcare providers.

The remainder of this thesis will provide evidence of research working towards addressing each of these questions, as well as outline future work in each area. Table 1 summarizes the research questions I plan to answer with my thesis, and the studies that will address them.

Table 1: Summary of proposed research questions and studies for the thesis

	Research Questions	How it was addressed
RQ1	How do pediatric asthma patients, caregivers, and healthcare providers currently use technologies to manage pediatric asthma in their own settings?	1) Qualitative study with in-depth interviews, surveys and observations of pediatric asthma patients, caregivers, and healthcare providers. [72, 73]
RQ2	Which characteristics of technology probes contribute to effective interventions for pediatric asthma management for children with asthma and their caregivers in a home setting, and how can we design them to improve pediatric asthma management?	1) Linking the characteristics of technologies and design implications from in-depth interviews, surveys and observations of pediatric asthma patients, caregivers, and healthcare providers. [72, 73] 2) Developing design ideas based on the results of technology probes for pediatric asthma patients and caregivers. [161]
RQ3	How do pediatric asthma patients and healthcare providers adopt a mobile and web service over the course of several months to improve asthma knowledge and awareness, and to affect the perceived quality of interaction with the healthcare providers, which can lead to improved quality of life and health outcomes?	1) System deployment study in which qualitative/quantitative data is collected from the clinical setting. 2) Hypothesis-driven field study in which design decisions are evaluated [160]
RQ4	What is the impact of socioeconomic status, as an independent factor influencing quality of life, on the effectiveness of a mobile and web service? How does that impact differ for improvements in quality of life and health outcomes between patients with public insurance and patients with private insurance?	1) System deployment study in which qualitative/quantitative data is collected from the clinical setting. 2) Hypothesis-driven field study in which design decisions are evaluated

1.2 Overview of Document

Chapter 2 reviews related work and establishes why it is important to design and evaluate ubiquitous communication services to support pediatric asthma management in the HCI field. Chapter 3 describes a series of formative studies to understand the current practices and challenges faced by pediatric asthma patients, caregivers, and healthcare providers. Chapter 4 describes technology probes to design and understand how pediatric asthma patients and caregivers adopted or adapted technologies we provided. In Chapter 5, I describe the design of the SMS service and Physician's Dashboard. In Chapter 6, I describe two field deployments of the SMS service and Physician's Dashboard, which are designed to address specific hypotheses. Finally, in Chapter 7, I provide a detailed discussion of two deployment studies, highlighting limitations and areas of future work.

CHAPTER II

BACKGROUND AND RELATED WORK

In this chapter, I discuss some background and related work in ubiquitous communication technology for pediatric asthma management. In addition to presenting background information on pediatric asthma management, I describe how my work fits into the areas of technology interventions in pediatric asthma management, ubiquitous communication technology for chronic care, and health-related theories. My research includes two distinct relationships: 1) children with asthma and their caregivers; and 2) children with asthma and their healthcare providers. My ubiquitous communication technology focused on supporting the second relationship.

2.1 Motivation

Chronic diseases are the leading cause of mortality and morbidity worldwide. It is accountable for 59 percent of deaths and 46 percent of diseases [31]. Despite improvements in the effectiveness of chronic care, research shows that patients often do not have access to the care they want [54]. Many healthcare providers describe that managing chronic conditions in pediatric or adolescent patients is more difficult than adults, and investment in education about adolescent development and healthcare needs is required [132]. Chronic illness care for the pediatric patients is especially disadvantaged compared to adults because children engage more often in risky behaviors, which expose the children to the potential for greater adverse health outcomes [132]. For example, pediatric asthmatic patients who are exposed to tobacco are at increased risk of pulmonary deterioration.

The importance of understanding and facilitating the transition of responsibility

for self-management during adolescence cannot be overstressed. Theoretical and empirical studies can identify the timing, speed, and nature of the shift in responsibility [132]. At the same time, the development of technologies supporting families and children with chronic conditions in managing their health has become an emerging research area [40].

Consistent and rigorous monitoring of health status would provide evidence for clinical and preventive efforts that help the management of chronic conditions for pediatric patients and their families [132]. The ubiquity of mobile phones and the increased computational and sensing capabilities have enabled continuous monitoring for health management. Examples include predictive and persuasive means of monitoring and reflecting health-related activities, either supporting general wellness [32], or to track main objective indicators of a chronic condition [103, 124]. Most of this past work required additional instrumentation that was coordinated through the mobile phone, with the promise that future smartphone platforms would contain all the necessary capabilities. These trends have augmented pediatric chronic care by enhancing the current practices and reforming relationships between pediatric patients and healthcare providers.

In my work, I focus on designing and evaluating ubiquitous communication technologies that assist pediatric patients with asthma and healthcare providers. Pediatric asthma management requires more and different stakeholders' involvement in care than similar adult conditions do [51]. The management has been a burden to family members due to time at doctor's offices and hospitals rather than at work, school, or home [142], and demands high-quality communication with healthcare providers [150]. All these aspects of pediatric asthma management make it a challenging condition and its management a process requiring the careful consideration of technology interventions.

2.2 Pediatric Asthma Challenges

Several challenges for pediatric asthma care have been revealed in the clinical literature because children with asthma are not identical, and everyone has a unique combination of asthma triggers and symptoms. Children with asthma and their caregivers should be aware of at least three types of asthma triggers, including environmental triggers (e.g., outdoor air pollution, pets, mold, secondhand smoke, and dust mites, etc.), physical triggers (e.g., strenuous physical exercise, some medicines, and some foods and food additives), and psychological triggers (e.g., strong emotional states). Environmental triggers, which children with asthma or caregivers cannot control directly, affect the patient's symptoms. Increasing concern over the effects of outdoor and indoor air quality on health exists in the scientific community. These concerns are even more pressing in the case of pediatric asthma. Thus, many studies investigate the role of air quality as an asthma trigger.

Sheppard et al. investigated the relationship between measured outdoor air quality in Seattle and nonelderly hospital admissions with a principal diagnosis of asthma. They found an increase in the rate of asthma-related hospital admissions associated with ambient pollutants [135]. Another study also looked at the association of outdoor air quality with pediatric asthma patient's symptoms. The result from the study suggests, " *Children with a prior diagnosis of asthma are more likely to develop persistent lower respiratory tract symptoms when exposed to air pollution in Southern California* [106]." Interestingly, pediatric emergency-room visits for asthma were reduced in Atlanta, Georgia, during the summers of 1993-1995 when traffic was reduced, and outdoor air quality improved [145]. This study supports a relationship between air pollution and childhood asthma exacerbation.

Indoor air quality is a powerful trigger for asthmatics. Indoor exposure to materials such as combustion products, and to pollutants emitted from building materials, impacts one's health [74]. Indoor air quality is closely linked to increased asthma

prevalence. While the understanding of environmental influences is still relatively limited, indoor exposures may be more influential than outdoor pollutants because children spend much more of their time indoors than outdoors [41]. Dekker et al. investigated the influence of indoor air quality on asthma. They verify that exposure to environmental tobacco smoke, living in damp houses, the use of gas, and the use of a humidifier are associated with childhood asthma [37]. Another study also reports that there were relationships between indoor air pollution and outcomes of respiratory morbidity related to combustion sources [121]. Thus, it is crucial that technology interventions provide asthma patients with information regarding indoor and outdoor air quality.

Taking medication for asthma is a challenge because there are at least two types of asthma medications: a control medicine to be used in a daily routine; and a rescue medicine to be used as needed in the right. It is essential for pediatric asthma patients to take asthma medicine appropriately [66].

In recognizing asthma symptoms, another well-known challenge in pediatric asthma management is discordance between children with asthma and the group of people explaining and guiding asthma management, since caregivers generally report fewer of their children's asthma symptoms than do the children themselves [96]. This may affect the ability of children with asthma to adhere to their asthma management regimen [61]. Thus, it is crucial that healthcare providers assess the status of asthma by directly communicating with the pediatric asthma patient. My research provides the means to support the communication and enables children with asthma to provide their status to healthcare providers easily.

2.3 Pediatric Asthma Management

Nearly three decades ago, a number of trends and forces converged, catalyzing the development of effective intervention programs for individuals with asthma. The self-management concept was further advanced by the recognition and acknowledgement of the health management process as a shared responsibility. Researchers developed and tested a number of self-management techniques, accumulating the body of experience and support for this treatment option [12].

However, promoting self-management is of little value for pediatric asthma patients unless the relevant and necessary support by healthcare providers reaches the individual and enables increased knowledge, awareness, and behavior change. Thus, collaboration between various stakeholders, as well as an understanding of the health reasoning of pediatric patients and caregivers, are both essential to the success of pediatric asthma management.

The clinical literature in pediatric asthma management indicates that there are several design challenges in this space. For example, children with asthma and their caregivers report different symptoms [96]. Caregivers tend to report fewer numbers of their children's asthma symptoms than do the children themselves. Research identified evidence of a gap between the children's knowledge and their behavior due to limited income and insurance coverage [148]. Heterogeneity of asthma conditions complicates the management of pediatric asthma [104] and medication adherence [66]. That pediatric asthma management requires an integrated approach for the child's ecosystem [28]. My research not only covers asthma management for children with asthma and their caregivers, but also investigates communication between children with asthma and healthcare providers.

2.4 Theories in Health Behavior Change

The increasing prevalence of chronic disease has provoked a greater emphasis on individual responsibility for health management. This emphasis has raised the need for understanding health behaviors by using theories [13]. Health behavior has been linked to different factors such as beliefs, expectations, motives, values, perceptions, and other cognitive elements [86]. Various theories or frameworks attempt to explain why health behavior change does or does not happen, and/or describe how these factors affect changes in behavior through various interventions. However, many studies of technology interventions did not use a theory to design and evaluate their impact on chronic care management. We need to investigate which theory might be fitted into specific interventions. Future studies need to explicitly describe the theoretical constructs being targeted in interventions. This will assist further testing and development of theory for chronic care as it applies to these new interventions. The lack of theory-based interventions may reflect the current focus of technology interventions on preventive health management rather than clinical care [47].

Researchers in HCI have adopted health-related theories and frameworks to design their interventions [33, 56], though these have been primarily preventive health studies. The Health Belief Model (HBM) [130], The Transtheoretical Model (TTM) [125], Social Cognitive Theory (SCT) [10], and other theories have been applied to design technology interventions to promote behavior change. I will explain the characteristics of each theory below.

The HBM has been one of the most widely used conceptual frameworks in health behavior research. The HBM explains how health-related behaviors are changed and maintained, and provides a framework for health behavior interventions [130]. The HBM includes some primary concepts that predict why people will try to prevent or to control disease conditions. The purpose of studies utilizing the HBM is to identify its usefulness coupled with other theories and frameworks [86].

TTM uses stages of change to incorporate processes of change from across major theories of intervention [125]. The TTM theorizes change as a process. The progress consists of a series of six stages to integrate processes of behavior change. However, children and adolescents might not be fitted into TTM extremely well since we still do not know when when intentional behavior change starts [86].

SCT highlights reciprocal determinism in the interaction between people and their environments [10]. SCT suggests human behavior is the outcome of the dynamic interaction of personal, behavioral, end environmental influences. This theory focuses on people's potential abilities to change and create environments for suiting purposes they invent for themselves. According to Bandura, "*planned protection and promotion of public health can be viewed as illustrations of this kind of reciprocal determinism, as societies seek to control the environmental and social factors that influence health behaviors and health outcomes* [86]." However, because SCT is very broad, it has not been tested systematically in the same way that some other health behavior theories have been tested. Only self-efficacy, SCT's best-known concept, has been tested [86].

2.4.1 The Health Belief Model

One of my research goals is to explicitly describe the theoretical constructs being targeted in my interventions. While all these theories have their own advantages, a theory that inspired us is the Health Belief Model (HBM) [130]. The HBM explains change and maintenance of health-related behaviors and guides the framework for health behavior interventions. This model includes several elements that predict when people will take action to prevent or control illness (see Figure 2). Two components that I investigate in my thesis are symptom awareness (perceived severity of disease) and knowledge acquisition. These two factors are crucial to individuals engaging in proactive behavior to improve their condition [130].

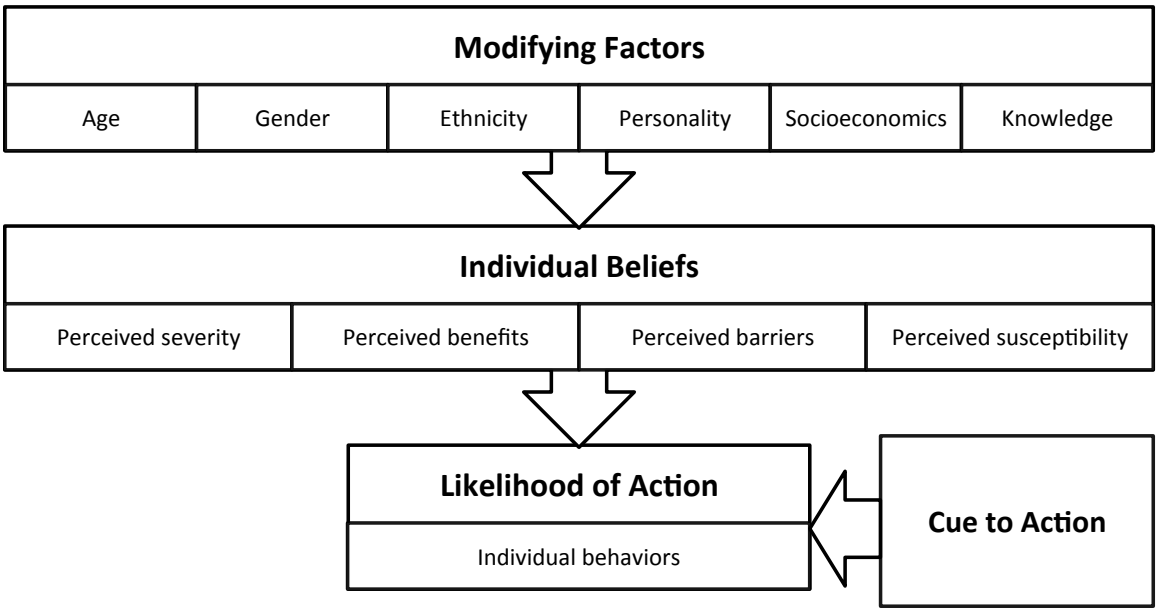


Figure 2: The Health Belief Model [13, 130, 131, 71].

2.4.2 Knowledge Acquisition in Pediatric Asthma Management

Patients with chronic conditions make conscious and/or unconscious daily decisions about things that directly or indirectly affect their conditions. This decision making has introduced a chronic disease management, which involves collaborative care and self-management education [18]. The National Asthma Education Program highlights patient education, which has been labeled as "critically important in the successful treatment of asthma" to improve health outcomes [156]. These education programs for various chronic illnesses can improve health outcomes and reduce costs [17].

Knowledge about chronic illness management is a prerequisite for well-planned chronic care. Education programs for chronic illness management produced small to moderate health improvements for several but not all chronic illnesses [154]. For example, a asthma trial, which is an education program to monitor disease activity and adjust therapy using the peak flow meter, showed reduced frequency of attacks [58]. However, the effects of arthritis education interventions did not suggest a significant benefit. While education interventions are theoretically appealing to empower

patients, improve health outcomes, and reduce health care costs, the findings in research showed that not all education interventions for all diseases are effective [154].

A meta review study shows that even complex education interventions targeting only behavior did not change health outcomes [151]. Thus, we need to clarify how the design of educational interventions can impact on the better health outcomes. Chronic disease interventions that positively affect patient chronic care should embrace systematic efforts to increase not only patients' knowledge, but also skills and confidence for controlling their condition [151].

2.4.3 The Role of Perceived Severity of Disease in Pediatric Asthma Management

A central line of research, investigating how the perceived condition of chronic disease affects the management of health, has tried to understand health threats and regulate behavior [133]. The studies investigating associations between perceived condition and health outcome have provided well perceived condition of chronic disease is related to better health outcomes, and a low level of perceived condition of chronic illness seems to be associated with positive outcomes [133].

In the Health Belief Model, perceived severity, "*feelings about the seriousness of contracting an illness or of leaving in untreated include evaluations of both medical and clinical consequences and possible social consequences*," is strongly related to the behavior of patients with chronic illness [86].

In asthma management, patients sometimes recognize the severity of their asthma rather poorly. This may cause problems for asthma management since underestimation of their conditions may lead to under-treatment and be potentially risky. Incorrect awareness of symptoms of asthma may result in delaying in beginning preventive treatment and in requesting medical attention [11]. Therefore, we need to investigate how the change of the perceived severity of conditions can affect behavior changes.

2.4.4 Communication in Pediatric Asthma Management

Communication is one of the significant elements of social influence and a critical process to support behavior change. Research supports the vital role of communication in fostering adherence to chronic disease regimens in the care of pediatric patients [38]. This communication may occur in either formal (healthcare providers and patients) or informal (friends and families) relationships. This is particularly relevant for patients suffering from chronic diseases because better communication may lead to better health outcomes [86, 85].

Clinical trials conducted among chronically ill patients demonstrated that physiological, behavioral, or subjective health outcomes were related to specific aspects of physician–patient communication [85]. The relationship between healthcare providers and patients may have a significant impact on health outcomes. We should consider changing current practices that may put this relationship at risk.

As many studies have shown, communication can be seen as the main factor in chronic care. One meta-review describes that the communication usually has three different purposes: "*(a) creating a good inter-personal relationship; (b) exchanging information; and (c) making treatment-related decisions* [119]."

This communication leads to better health outcomes such as improved knowledge and understanding, improved access to care, and a stronger alliance between healthcare providers and patients [86]. The models of communication might be straightforward enough to guide research. However, it is complex to simulate clinical practices, and research involving technology interventions targeted to improve communication and health behavior with pediatric patients is rarely conducted [38]. Thus, we need to test the importance of these functions and how they impact health outcomes.

2.4.5 Intervnetion Evaluation: Quality of Life

Quality of life is often measured in health intervention studies. We often use functional status and quality of life to assess the effectiveness of health interventions. The definition usually depends on why we are assessing health [60]. Healthcare providers are normally using conventional measures of asthma (e.g., symptoms, β-agonist use, and pulmonary function) to assess patient's status. However, recent research has shown that quality of life is a distinctive characteristic of asthma management, which is not closely correlated with asthma control [82]. This is the reason why we use a child's quality of life instrument, because: 1) we cannot infer the quality of life from the conventional clinical outcomes; and 2) we need to understand how interventions work from the perspective of both well-being and clinical outcomes. For simplicity, I am using " *the functional effects of an illness and its consequent therapy upon a patient, as perceived by the patient*" as the meaning of quality of life, as defined by Schipper and colleagues in these studies [141].

Quality of life is an especially vague expression, which often means different things to different individuals. Thus, it is hard to define the term. Most researchers agree that many factors, such as income, home environment, parental support, and health contribute to quality of life, and that each of these factors also affects the others [83]. Low income, the lack of freedom, or a low-quality environment may negatively impact health [59]. We use the term quality of life to include the factors that we consider here.

Common medical practices have three main goals for treating patients: 1) to prevent them from dying; 2) to reduce the risk of long-term organ damage; and 3) to improve their well-being [59]. Typically, the conventional clinical outcomes (e.g., pulmonary functions, symptoms, etc.) are used to assess asthma management through clinical practices [79]. We can use these measures to assess whether we achieved the first two goals or not. We assumed that these clinical outcomes provided the

understanding of patients' "quality of life", and the result of the study showed that pediatric patients with severe asthma have worse quality of life than patients with a mild condition [82].

Different factors can affect quality of life. First, self-efficacy can be a mediator for quality of life. Cunningham et al. found by using their developed instrument that perceived self-efficacy, which is the "perceived ability to enact coping strategies", and quality of life are strongly interdependent attributes in cancer patients [35]. Another study investigated the role of self-efficacy in the relationship between pulmonary function outcomes and quality of life measures because there were inconsistent correlations between the latter two [89]. The authors found that perceived self-efficacy mediated the association of pulmonary function with quality of life among patients with chronic obstructive pulmonary disease. The role of self-efficacy as mediator was confirmed by another study of patients with asthma, diabetes and heart failure [92]. This study reported that "self-efficacy in achieving desired health outcomes was found to mediate the association between discrepancy in illness related goals and the subscales for quality of life and well-being. In other words, higher discrepancy between importance and attainability of illness-related goals was associated with lower self-efficacy in achieving desired health outcome [92]." Since many studies use self-efficacy as one of the outcomes, we can think of using self-efficacy as an alternative measure instead of PAQLQ. However, I do not explicitly use the self-efficacy measure in my study, since I was using ATAQ, which can assess the perceived self-efficacy [138]. Second, demographic data is one of the factors associated with quality of life. Specifically, household income was found to be a significant predictor of having a better quality of life [9, 118]. Erickson identified that household income was most consistently correlated with PAQLQ and PACQLQ[43], and he showed a positive significant association between income and Activity Limitation in quality of life [42]. Thus, we should consider household income as a unique factor to identify how technology intervention can

be beneficial based on household income.

2.5 Health Management in Ubiquitous Computing

Twenty years ago, Mark Weiser envisioned the future of computing called "*Ubiquitous Computing*" [155]. This vision inspired many research ideas. Weiser's vision of Ubiquitous Computing was to create a world where our interactions are supported by computationally-augmented artifacts. Ubiquitous computing, Weiser argued, should be so absorbed into everyday life that the artifacts "disappear" from our conscious observation. In the passage of twenty years, we have witnessed the birth of various technologies such as mobile phone infrastructure, smart phones, the World Wide Web, and cloud computing. However, in recent years, we have not achieved these Ubiquitous Computing (ubicomp) visions. Nowadays, the ubicomp community raises several critical views of Weiser's vision. I discuss these perspectives below. These views motivated my work and thoughts in designing and assessing technologies in this dissertation.

Yvonne Rogers examines the emphasis on calm computing that inspired research in anticipating the needs of users, while focusing on human-centered computing: "*We should consider how ubicomp technologies can be designed to augment the human intellect so that people can perform ever greater feats, extending their ability to learn, take decisions, reason, create, solve complex problems and generate innovative ideas* [128]."

This critical view of Weiser's vision is coupled with the ideas of designing technologies in my work, since use of a technological intervention can raise awareness and change their knowledge while awareness of the technology disappears.

Other researchers realized that we had already achieved the vision of ubicomp in a different form than Weiser expected [14]. For example, mobile communications and the World Wide Web are now integrated into everyday life. It means some

technologies have reached some degree of ubiquity. This reality inspired investigating what kinds of technologies are available to users in my research.

2.5.1 Technology for Asthma Management

Self-monitoring is a crucial part of chronic care management and is shown to be an effective method for health behavior change [103, 139, 102]. Technologies for self-monitoring automatically can collect and visualize the physiological measure of interest. Reflecting on the history of their behavior or outcomes should allow patients to track issues and connect changes to things they do differently. On a psychological level, recent studies investigated the use of ubiquitous computing technologies to help patients monitor their recent symptoms [103, 70, 127]. Using the system allowed patients with diabetes to achieve their self-management goals. However, this research was conducted for adults. Thus, the question still remains whether similar technologies can be effectively applied to pediatric patients who may have a vague sense of responsibility and inadequate knowledge of self-management.

The mobile phones with increased computational and sensing capabilities have become an ideal experimental platform for mobile health research. Researchers have used the mobile phones to support general wellness [32] or to trace the status of a chronic condition (e.g., glucose levels or drug dosage) [103, 124]. However, Most of this work required additional instrumentation coupled with the mobile phone.

To avoid additional hardware and software requirements, researchers have opted to use the short message service (SMS) that is readily available on mobile phones. One study offered patients simple text message reminders for taking medication, which helped patients comply with daily medication regimens [115]. The Centers for Disease Control (CDC), has used SMS to provide information about HIV test centers, and to deliver weekly flu maps across the United States[1]. Text4Baby is an

[1]http://www.cdc.gov/widgets/SMS/alt/

educational program of the National Healthy Mothers, Healthy Babies Coalition that provides a free mobile information service designed to promote maternal and child health.

Data plans that allow access to general Internet services are available via mobile phones, though not as prevalent as SMS service. An early use of this capability for mobile health was a web-based asthma diary study where patients could enter information concerning their asthma symptoms and medication use [7]. The asthma diary improved interaction between physicians and patients when used, but patient reporting diminished over the duration of the study because Internet use was not part of the participant's everyday life. A follow-up study addressed the issue above by using both a web-based diary and SMS [6].

One trend in intervention for asthma management has been to focus on technologies such as the Internet and mobile phones to support self-reported diaries. A written diary typically includes subjective and objective assessments of the severity of the disease. Self-reported diaries are preferable to questionnaires or clinic-based consultations. However, accurate recall of symptoms may be affected by memory bias. Hyland et al. reported that symptom diaries of patients with asthma are also inaccurate because they are typically based on retrospective recall [68]. The authors report that incorrect diary entries produce incorrect medical prescriptions and instructions. They concluded that electronic-based diaries could improve the quality of records by supporting accurate completion of a diary and reducing human forgetfulness and error.

Telemonitoring is another current trend in intervention for asthma management. Technological applications include web-based telemedicine systems for asthma self-management [33] and asthma diaries through mobile phones [6]. These systems help not only the individual to monitor asthma symptoms but also healthcare providers to monitor their patients' status. Finkelstein et al. evaluated the validity of spirometry

self-testing and assessed the acceptance of an Internet-based home asthma telemonitoring system [45]. They deployed Internet-based telemonitoring systems at patients' homes for three weeks in a low-income inner-city area. They found that spirometry self-testing could be valid in a group of patients with no computer background. The results showed that patients using the internet-based telemonitoring system had higher compliance to asthma action plans than those who had only standard care.

Another study designed an Internet-based asthma self-management and education program to enable children to track their asthma symptoms and quality of life. This information was sent to health care providers [57]. Compared to individuals who used an asthma diary, the individuals with the Internet-based system showed increased self-management skills and improved asthma health outcomes. However, this study did not provide a reason why the Internet-based system was effective. A meta-analysis also found that patient knowledge and behavioral change outcomes are increased with Internet-based interventions as compared to outcomes from non-Internet-based interventions. The result depicts an improvement related to the participants' ability to acquire specified knowledge such as knowledge of asthma treatment [153].

Technology-based studies have limitations. In one study, patients were given access to a web-based diary system that allowed them to monitor their asthma and to record their management strategies. In the diary, the patient entered peak flow values, number of doses of rescue medications, and other asthma-related data. The system gave patients feedback about their health status. Healthcare providers were given access to their patient diaries. However, participants only used the system on a limited basis. Researchers reported that patients did not fit the system into their everyday lives for a variety of technical and psychological reasons [7].

In an attempt to overcome the limitations of their first study, Anhj and Mldrup investigated the use of Short Message Service (SMS) to support self-management of asthma [6]. Here, the goal was to integrate the data recording into an individual's

daily routine. The result from this study showed that diary data collection via SMS is feasible and that SMS may support the self-management of asthma because a cell phone, unlike a desktop computer, was a part of everyday life for the participants.

SMS has added to the discussion about the relevance of peak flow meter use. A standard tool for asthma management is a peak flow meter, a portable, inexpensive, handheld device used to measure the ability to push air out of the lungs [4]. Asthma guidelines recommended daily peak exploratory flow (PEF) measurements to check the lung status of patients with asthma. However, the literature has mixed findings concerning the relevance of peak flow meter use for improved asthma status. One study indicated that using a peak flow meter without a system of self-management would be unlikely to improve patient care [26]. Another study shows that adherence to long-term daily PEF measurement for asthma management did not have a large impact on health outcomes [75]. However, another study suggested the type of peak flow meter affected reliable measurement. These researchers suggest that if we use peak flow monitoring for pediatric asthma management, only electronic peak flow meters, rather than manual ones, should be used since pediatric patients sometimes record wrong values with manual ones [84]. One of these studies concludes, "*SMS is a convenient, reliable, affordable, and secure means of telemedicine that may improve asthma control when added to a written action plan and standard follow-up* [120]."

In conclusion, the literature review suggests that the combination of an Internet-based system and SMS data collection might be a more useful tool for patients than using only one technology. However, few studies investigate the combination of approaches [95]. Thus, my research investigates the combination of SMS and web service.

2.5.2 Communication Tools for Chronic Care

Following the increase in mobile device use, mobile applications for chronic care are increasingly being researched [158]. For example, a wide deployment of communication devices can support the communication of health information. Patients, caregivers, and healthcare providers can use computing devices anywhere and, thus, have the potential to send or receive health-related information anytime [69]. One of the current health management areas where a mobile application has been employed is in supporting communications between patients and physicians [140]. Communication tools to support patients and health care providers include: 1) telemonitoring, to monitor patients from a distance; 2) teleconsulting, to enable consultation between geographically separated individuals; and 3) patient education [93]. The dominant technologies to support communication include web applications, e-mail communication, and mobile phone (SMS and voice mail). Some studies for general health management or chronic care were assessed in ecologically valid settings, but they provided patients with additional digital equipment, and did not directly assess health outcomes [32]. Another challenge is that the communication mechanism needs to fit into the daily routines of clinical practitioners [93]. Evaluation of novel technologies in clinical settings is also challenging because labor is costly and highly distributed across space and time in clinical settings, such as doctor's offices and hospitals [44]. Emerging technologies change the patient–physician relationship. This change might lead to improve the quality of pediatric asthma management. My research investigates how ubiquitous communication technology affects the perceived quality of interaction with the healthcare providers, which can lead to improved quality of life and health outcomes.

2.5.3 Asthma Care Technologies for Low-Income Children

Since pediatric asthma management requires financial resources, education, and healthcare providers, asthma disproportionately affects low-income and minority populations [46]. Poor children usually have 40% higher rates of hospitalization and 40% lower rates of preventive ambulatory services. Additionally, low-income households possess low health literacy regardless of actual literacy [156]. Simply providing Medicaid insurance is not enough to ensure access to care [129].

Consequently, many investigators have explored pediatric asthma management strategies that focus on these high-risk populations. Effective outpatient care is one of the solutions to prevent adverse health outcomes for high-risk populations. However, these populations typically rely on acute care instead of routine preventive care [87].

To address the needs of pediatric asthma patients in these populations, previous researchers developed and evaluated interventions including asthma education and outreach programs in various settings. However, few controlled studies have been conducted in low-income populations [101, 87]. There has been a call in the literature for future studies to consider the arrangement of the delivery system, particularly the availability of continuous care for these population [129].

Previous research on healthcare technologies for families has focused on a wide variety of populations, including diabetics, elders, pregnant women, and children with special needs [72]. For instance, mobile applications facilitated synchronous medical communication between healthcare providers in supporting medical treatment to diabetic patients at home [97]. Another example used interactive web sites to support asynchronous communication between families and physicians for pediatric patients in an intensive care unit [20]. Additionally, teams of professional and family-based care providers cooperatively monitored health-related activities and shared the activity information in their daily routines with other relevant people through a variety of communication technologies [34]. However, challenges still exist for providing high

quality care in teams, particularly for those as diverse as the teams supporting low-income children with asthma [109, 62].

Although studies have shown that communication technologies can support co-operation among complex care teams, the multitude of people involved in caring for pediatric asthma complicates this communication in low-income population[72]. When health technologies are built to consider children, they typically target educational interventions rather than truly incorporating children into the communication and information sharing practices [116]. Thus, we need to understand how ecological settings around pediatric asthma patients work, and design technologies based on these understandings.

2.6 Summary

Previous work within the domain of technology interventions for pediatric asthma management points to three areas for future research. First, it shows that more studies should target various types of stakeholders. The majority of the previous interventions has been targeted to adult patients. It is necessary to conduct investigations, specifically with pediatric asthma patients and healthcare providers because pediatric asthma patients have issues to deal with their asthma, and unique relationships between stakeholders that may make it difficult to generalize findings from other settings. Second, more studies are needed to explore the combination of existing ubiquitous technologies, although there have been a plethora of studies that examine a specific type of technology coupled with health-related theories because different stakeholders in pediatric asthma management might have different technologies available to their practices. The combination of existing technologies in pediatric asthma management (for instance, the arrangement of Internet-based systems and mobile systems as a communication tool) remains relatively unexplored. Third, technologies for chronic care tend to focus on the actual behavior changes rather than constructs

that affect behavior change and their outcomes. The findings presented in this thesis research provide insights by focusing on how specific constructs supported by technologies address the limitations of the current practices and provide opportunities for future ubicomp applications in chronic care settings.

CHAPTER III

UNDERSTANDING OPPORTUNITIES FOR TECHNOLOGIES IN PEDIATRIC ASTHMA MANAGEMENT

In this chapter, I identify how technologies can improve pediatric asthma management and support the unique characteristics of pediatric asthma management. I discuss results from studies encompassing field observations, stakeholder interviews with families with asthmatic children and healthcare providers, and a focus group with community health workers. The study provides an initial set of answers to following research question:

RQ1. How do pediatric asthma patients, caregivers, and healthcare providers currently use technologies to manage pediatric asthma in their own settings?

This study did not have specific hypotheses since it was an initial exploratory study. The result of the study offers two main contributions. First, the study revealed the fundamental challenges of pediatric asthma management, as well as the current practices of children with asthma and their caregivers for managing asthma. Second, I conclude this chapter by outlining potential design opportunities and highlighting a path for other technologies to play a role in pediatric asthma management.

3.1 Introduction

Computing technologies help manage chronic diseases by using personal healthcare records, observing patients, and supporting telehealth and telemedicine systems. Design implications for computing technologies related to healthcare and chronic disease

management have been actively explored for various disease conditions such as cancer and diabetes. Some studies have targeted diverse population groups, such as the elderly and children with special needs [64, 103, 111]. However, many studies do not address aspects of the most common chronic pediatric illness, asthma. Pediatric asthma management is one of the most important public health issues. Active discussions center on how to avoid complex asthma triggers, how to take proper medicines, and how to encourage patients to self-control their asthma symptoms. My goal in this study was to identify opportunities for supporting pediatric asthma management.

3.2 Method

The aim of the study was to assess the current management strategies and challenges involved in pediatric asthma management. My colleagues and I investigated multiple stakeholders: pediatric asthma patients, their families, healthcare providers, and community workers. Based on a qualitative empirical approach [15], our research methodologies included observation, shadowing, interviewing, and photo journaling. Since asthma rates appear higher in urban areas, we conducted our studies in Atlanta. In particular, Atlanta is one of the top ten most difficult cities to live with asthma in the U.S. (aafa.org). We recruited interview participants through flyers at a pediatric pulmonology practice, an asthma public seminar, an asthma free screening service event, and Craig's list (craigslist.com). Finally, we interviewed 21 people including 6 healthcare providers, 8 children with asthma, and their 7 caregivers. We planned for random recruitment. However, perhaps due to the high concentration of asthmatic population in the African-American community, all of our participants in home visits came from this community. We explicitly asked for help to recruit other ethnic groups from local practitioners, but did not succeed. Before interviews, all participants signed consent forms that allowed us to interview, take notes, audiotape, and partially videotape interviews. We interviewed each healthcare provider

Table 2: Interview participant demographics.

Caregivers and Their Children with Asthma			
Family (Ethnicity)	**Interview participant (Current Age: occupation / Education) *Every child is on Medicaid**	**Child's Asthma Severity**	**Internet at Home (Mobile) Phone**
Family 1 (African American)	Divorced mother (36: Registered nurse / Graduate)	Severe	Y (Y)
	Girl with asthma diagnosed at 3 yrs-old (9)		
Family2 (African American)	Single grandmother (64: Retired / Graduate)	Moderate	Y (Y)
	Boy with asthma diagnosed at 4 yrs-old (13)		
Family3 (African American)	Married mother (35: Administrative assistant / College)	Moderate	Y (Y+SMS service)
	Boy with asthma diagnosed at 1 yr-old (12)		
	Boy with asthma diagnosed at 1 yr-old (10)		
Family 4 (African American)	Married mother (36: CNA/Phlebotomist / College)	Moderate	N (Y)
	Boy with asthma diagnosed at 2 yrs-old (7)		
Family 5 (African American)	Married mother (34: Supervisor / High School)	Severe	Y (Y)
	Girl with asthma diagnosed at 2 yrs-old (8)		
Family 6 (African American)	Single mother (45: Unit secretary / College)	Severe	Y (Y)
	Boy with asthma diagnosed at 5 yrs-old (11)		
Family 7 (African American)	Divorced mother (41: Student / College)	Severe	Y (Y)
	Girl with asthma diagnosed at 2 yrs-old (7)		

Healthcare Providers		
No.	**Occupation / Gender / Ethnicity**	**Career years**
HP 1	Respiratory Therapist / M / Caucasian	20
HP 2	Physician Assistant / M / Caucasian	4
HP 3	Nurse / F / Caucasian	19
HP 4	Nurse /Certified Asthma Educator / F / Caucasian	10
HP 5	Pediatric Pulmonologist / F / African American	5
HP 6	Allergist. / M / Caucasian	15

during a 30-minute session in their office (except for one interview over the phone). For an in-depth interview with families, we visited 7 households. At each home, we spent 90 minutes interviewing children with asthma and their caregivers together, and compensated with a $25 gift card. We summarize the demographic information in Table 2. In order to maximize the benefits of the in-depth interview at home, we used three interview methods: participatory design [15], projective technique[16], and a home tour with a semi- structured interview questionnaire. Interviewing participants during the home tour prompted them to actively describe different asthma management strategies and device usage at each room. It helped us have insights and find needs on potential opportunities for ubicomp technologies related to home environments.

3.2.1 Observation

We conducted preliminary fieldwork. We observed five asthma related events including an asthma education program for medical professionals, a public seminar that provides general asthma information, and three free asthma screening services. These events typically lasted four to five hours. During the observation, we met as a team afterwards to debrief and discuss our observations. In addition, we shadowed two medical professionals in a local clinic over a four-week period. We also shadowed two community health workers (CHWs) in their offices and during in-home visits over three weeks. This preliminary fieldwork included a total of 32 hours of observation over six months. During the shadowing, we focused on observing how professionals communicate with each other and with families with pediatric asthma.

3.2.1.1 Children with Asthma and Their Families

We conducted home visits in 7 homes. Each home visit took approximately 90 minutes including semi-structured interviews with 10 children with asthma (aged 7 to 13) and their nine caregivers and a photo journaling home tour. We recruited participants through local clinics and Craigslist. Additionally, we interviewed two caregivers who have children with asthma at a free asthma screening service in a church. The questions focused on the participants' general experiences with pediatric asthma, how they share their experiences about asthma care, and how they use tools to communicate with each other. We also asked participants to describe satisfaction levels with current pediatric asthma care practices. Lastly, we asked a series of specific questions about challenges and wishes of pediatric asthma care with collaborative care teams.

3.2.1.2 Healthcare Providers and Community Health Workers

I reached beyond the asthmatic children and their families and worked with healthcare professionals and social workers to understand asthma management. We conducted interviews with six medical professionals, including a pediatric pulmonologist, an

allergist, a nurse practitioner, a respiratory therapist, a physician assistant, and a certified asthma educator who was a registered school nurse, in all their offices (except for an educator who did a phone interview). Additionally, we shadowed healthcare providers as they went through their daily routine of seeing patients, interacting with other staff members and managing their practice (writing prescriptions, checking emails, and entering data into the electronic medical records of their patients) [28].

3.2.2 Analysis

I employed an inductive qualitative analysis approach [143] (similar to thematic or affinity analysis) to identify emergent themes pertaining to the design of technological solutions to address the needs of children with asthma, their families, and healthcare providers. All interviews were audio-recorded and transcribed. We analyzed all collected data such as interview transcripts, field notes, photographs, and asthma related materials from field investigations. Through a group meeting, we categorized themes into five major needs for each stakeholder and three strategies that support their needs in our findings. During this process, we used hand-drawn diagrams, sticky notes, and Atlas.ti to document the themes and coding schemes.

3.3 Findings

In this section, I present the challenges people experience in managing asthma in their everyday lives. I describe the tools and strategies that families have adopted to address those challenges. I present opportunities for technologies to enhance current pediatric asthma management.

To prioritize major finding categories in analyzing the data, we counted how often each theme was mentioned, and how many participants mentioned the themes. We did not attempt to generalize our results but to apply a systematic approach to our qualitative data analysis. We highlight the similarities and differences between the needs of our various stakeholders with regards to how technology can be used to

manage pediatric asthma. In general, if we look at the distribution of needs that were sited in the interviews, we see that adults are more similar to each other than are the children. Adults generally agreed that technology could be used to enhance personalized management of pediatric asthma. That technology could be used to provide the caregivers (both parents and healthcare providers) with a communication and reminder tool. Adults also agreed that this tool could be used to persuade positive behavior changes.

Differences between the caregivers and healthcare providers appeared evident because parents, on average, voiced more needs. For example, caregivers in contrast to to healthcare providers and children, were more concerned with controlling asthma triggers and understanding what these were. They indicated that emotional support could become an important component of a technological aid. This was something that was not mentioned by either health providers or children. Caregivers also expressed more concerns about long-term asthma management when compared with children and healthcare providers. All parents mentioned the need for a tool that would help them know if they were reliably administering the medication. Parents also spoke of the desire to have an integrated data management scheme that might work better than what they had used, such as notepads and paper reminders on the fridge. Additionally, parents noted a need for an integrated information repository, and a fun way to engage their children in learning about asthma. Finally, they indicated that asthma management practices could be impacted by social media tools to share the knowledge they had acquired from living with their asthmatic children.

Children were not as communicative as the other two stakeholders perhaps because of their age or their parents' being present during the interview. Their data confirm that technology should induce fun, allow personalization and be able to integrate the various aspects of their asthma management.

Next, I describe our findings from the data analysis and present five themes we

have identified:

1. Control Complexity at Home
2. Challenges to Self Management
3. Excessive Information to Process
4. Emotional Stress
5. Little Access to Community Support

3.3.1 Control Complexity at Home

Asthma triggers vary by individual and can encompass one or more attributes in our everyday lives, such as pets, dust, chemicals, and insects. The caregivers in our study expressed difficulties with controlling the asthmatic symptoms because asthma triggers are often hard to define and contain. Additionally, they noted that trigger management became more challenging as many of the triggers were deeply interwoven with environmental factors such as air quality, pollen, humidity, and temperature that allow little space for human control. These triggers dynamically changed over time, place, and personal condition, and therefore the caregivers had to constantly pay attention to what additional components might induce asthma incidences. Also, we learned that the trigger control became even more complex when children had allergies, which can flare up children's asthma (lungusa.org). Allergy triggers mentioned by the children in this study include grass, dietary foods, nuts and so forth. These impacted daily activities, such as eating, playing, walking, and sleeping. Parents added that the allergic triggers appeared and disappeared over time as their children grew, and therefore felt stressed to track what their children could or could not do.

Healthcare providers also understood the complexity of the trigger management, and explained that the environmental condition of the low-income community aggravated this challenge. According to a respiratory therapist (HP1):

"...some families (of the low-income) live in an environment where they are exposed to a tremendous number of triggers. They have a leaky roof. They have dirty worms at their homes. They have problems with their pets. They have a poor diet. They have things like that. The poverty is a tremendous trigger for asthma. Asthma is a social disease."

In-home control for asthmatic symptoms seemed more complex than following the medication instructions. More than monitoring accurate dosage, caregivers primarily cared about how they could reach medicine on time in an emergency situation. Consequently, when prompted about how they controlled asthma triggers, caregivers mostly told us about how they placed medications in visible places, bought multiple inhalers, and got into the habit of carrying the asthma action plan (the personalized instruction about actions patients have to follow in an asthma episode) wherever they went with their children. For instance, one mother with a severe asthmatic child bought 12 inhalers and kept them in each room, and in each householder's belongings such as a purse and car. She did so to be able to access one without delay in a time of need.

For the environmental triggers that caregivers had little control over, they would organize a child's activities around the circumstance. For example, caregivers checked weather, pollen, smog, and ozone level from media before allowing the child to engage in outdoor activities. Also, they closely observed when seasons change as the increase or decrease in temperature and humidity can lead to increased symptoms. For instance, one mother gave extra dosage to her daughter before she went out for Halloween trick-or-treat, based on previous experiences that the child had asthma incidences most frequently around late October. Further, caregivers of asthmatic

Figure 3: Photos from home tour (Left: labeled food container, Right: asthma pack).

children put much effort into keeping the house clean. For instance, one parent kept six vacuum cleaners in the home and had sanitizing material in each room. They bought an allergy-free mattress cover, pillow cover, blanket, and even began to change carpeted floors to hardwood ones.

Diet was another element that caregivers paid attention to in managing children's asthma. One mother had to read all the ingredients in the food she purchased to avoid allergens that flared up her son's asthma. And she kept the food that he could eat in separate containers with his name on so that he would know what he could and could not eat (Figure 3: Left).

Despite the extensive efforts, challenges still remain. Caregivers expressed particular concerns about how to manage when their child was away from home, and stayed in places that had not been asthma controlled, such as schools and a friend's house. As a solution, schools and caregivers actively utilized mobile technologies. Caregivers gave a mobile phone with a prepaid service to their asthmatic children for emergency situations. Schools also did alerts by phone to caregivers if the weather or the heat index changed. Additionally, we saw creative solutions, such as a portable bag, referred to as an asthma pack that contained medicine, inhalers, asthma action plan and any other necessary artifacts to control the symptoms (Figure 3: Right). In five out of

seven home visits, participants talked about and showed us this bag. They added that this pack became useful even in their home when multiple family members had asthma, as it prevented the various types of medicines from getting mixed. However, they often forgot to bring it back from relatives' and friends' houses.

Thus, caregivers modified various parts of their domestic lives to manage the persistent asthma triggers that came from multiple sources. However, they considered the complex control measures as necessary, wanting to keep up with all possible ways to control reactions because, as one mother put it, they would "*rather be safe than sorry.*" Participants noted that such hyper-vigilance came at a price. It increased daily stress on both caregivers and children.

3.3.2 Challenges to Self Management

Asthma is a chronic disease that children have to deal with their whole life, so parents strongly desire that their children know how to manage the symptoms by themselves when they grow up and live independently. Even when they lived with parents, they taught children to manage by themselves due to their busy work schedule. More specifically, caregivers wanted children to understand how to prevent asthma attacks, to know what to do when it flared up, and to be able to balance between performing physical exercises and preventing asthma triggers. Further, parents felt the need for self-management because certain aspects of administering medication seemed best done by the child, such as feeling lung emptiness and then waiting several seconds before inhaling. Therefore, parents and healthcare providers tried to educate children to learn the process accurately.

To be able to independently manage the complex asthma-related problems, children needed to receive an extensive amount of education. Yet, the caregivers described that given their children's nature (e.g., wanting to play despite their physical condition), self management by the child became more challenging. Healthcare providers

addressed similar concerns in educating children, and explained that they introduced fun factors in the process, such as making it game-like. One child told us about the games he played in the hospital; he used a spirometer as a game in which he had to blow his best to blow a balloon. At home, they encouraged their caregivers to make the supervision and instruction time less as a lecture and more a collaboration. A physical assistant said (HP2):

"I think that some things that parents do well at teaching their children is...actually saying, 'It's time to do your medicine. Let's do it together.' I like it when parents are actively involved like that."

Currently, researchers and other online support groups offer numerous types of interactive games to educate children in home [1]. However, in our interviews, none of the children had played any of the games or had known of their existence. Our study did not show why they did not know about the games and did not play even when they knew. Given the perceived value of the game-like approaches in asthma education, we call for more research to understand this problem.

3.3.3 Excessive Information to Process

Healthcare providers played an important role in asthma management. They prescribed medications to children to control the reaction to known triggers. In our study, all children took at least two types of medications on a daily basis. Not only did the healthcare providers prescribe the right medication, but they also took responsibility for educating caregivers and children in daily management. They held an education session for the caregivers who visited the facility, distributed brochures, and introduced a game-like information session for children. In addition, they created a large poster in the exam room that had a picture of all medicine so that caregivers could become familiar with the medicines they currently used or would use.

The education primarily focused on accurate and consistent medicine intake because they had to track whether the symptoms became better or worse because of the medication or because of the triggers. The healthcare providers commented that tracking the symptoms and understanding what caused the changes were critical as asthma was a chronic disease that required long-term and persistent care. One said,

"They do not have good inflation technique. They do not know how to empty their lung and how to actually inhale this medicine. I guess the biggest problem is the overcoming some of these misconceptions and stressing how important it needs to do this properly."

Thus, they stressed the importance of precisely adhering to the instructions, which seemed to remain as a large challenge. Each medication they prescribed had different functions; some were preventive while others aimed to rescue in emergency situations. Nevertheless, healthcare providers reported that parents tended to judge the needs for medications by the amount or numbers that the child had to take at a time, such as more medicine when in a severe condition and vice versa. In general, the parents that we interviewed desired to minimize the amount of medications that their children had to take. The parents of the children who took steroids spoke strongly of such desire because they saw visible behavioral changes, such as frequent mood swing and more aggressive attitudes. Also, this type of medication seemed to affect children's appetite and began to pose weight problems. Consequently, parents tended to quit or decrease the number of medication intake when the asthma seemed milder and in control, which healthcare providers reported as "the biggest mistake". HP3 says:

"Probably the biggest mistake is they stop maintenance medicine...as soon as the child starts doing better then they stop everything and then all of a sudden they get sick again because some of those medicines were prevention medicines... We have a lot of patients who come in, and you can just tell they do not even know the name of their medicine."

To raise such awareness and to help retain the information learned, healthcare providers distributed written documents that explained how often children should use their medication, and what to do if they coughed. In households with asthmatic children, we also saw a stack of educational materials they received from healthcare providers in a dedicated box. However, the lengthy documentation kept in a remote place decreased the accessibility. Healthcare providers understood the problem and tried to summarize the information on one sheet of paper so that patients could place it on the refrigerator or on the bathroom mirror to get a daily reminder. Also, they made explicit suggestions for how to incorporate medication practices into their daily routine. One physician assistant (HP2) showed us an instruction that illustrates the medicine intake as a part of the nighttime routine, such as taking a medicine, brushing teeth, putting on pajamas, and then going to bed.

3.3.4 Emotional Stress

When we interviewed caregivers at home, participants rated the level of asthma impact on their lives on a 7-point Likert scale where 1 meant none at all and 7 meant the greatest impact. Five out of seven parents marked the highest impact. In addition to the extensive management of asthma triggers, parents had to spend a significant portion of their personal lives managing other sources of stress.

Children underwent emotional stress from the days they had to miss school when they were ill. Also, they experienced many limitations in the activities they desired to do, such as playing basketball. One mother of four asthmatic children told us how she gave instructions not to consume cheese and dairy for them, and to prevent participation in physical exercises. These limitations sometimes seemed to make children feel that they could not *"live normally like other children"*. As a result, we heard incidences where children refused to use inhalers and did not ask for timely help in school or at church as they did not want to appear different. One child

even began psychological consultation due to the depression coming from not being able to live as their healthy brothers and sisters. Parents understood and tried to support such normalcy in their children's lives. For example, they sent their children to Asthma camp and let them enjoy outdoor activities. Healthcare providers agreed and noted that the focal point of asthma control and education was not to limit the child's activity to prevent triggers, but to allow a way for children to live normally, particularly since they would likely stay with those symptoms throughout their lives.

Parents described stress from the heavy toll of managing their child's asthma. Caregivers also had to miss several days of work when their child was sick. Perhaps because we focused on the low-income households, parents described the emotional tension between wanting to stay close to the children and having to work very hard (including multiple jobs a day) to support the family. In addition to work, caregivers gave up on personal time, such as going on a vacation. One mother (P1) told us the difficulty of traveling because of the extensive amount of planning required to ensure the control of the child's asthma in a remote place. While recollecting the latest trip to Florida, she explained:

"...before we went and stayed at the resort, I had to talk to management... (the daughter with asthma) had to be put in a special filtration room, and then we had to be acclimated to the climate... we had to request special mattresses and stuff like that. It is not like we can just jump up and go stay at a hotel. We have to be really watching what's going on."

Parents also reported much emotional stress when they saw their children developing asthmatic episodes. All caregivers we interviewed had the experience of taking their child to the emergency room and felt the fear of losing their child. Such fear continued to stress them because they could not predict when the next attack would occur. The participating caregivers had some strategies of measuring the incidence, such as carefully watching for changes in the child's activity level and listening to

the coughing patterns. Still, they wanted more accurate measures that would allow them to treat their child when an episode broke out. Further, they explained how the emotional stress from a sudden attack could prevent them from adhering to the appropriate medication regime. One mother (P4) said:

"...there's been a time he has had (asthmatic episodes), and I was told to give him the EPI. I could not even do it. He started crying, so I started crying... He was okay, but you will panic when it comes down to your child. (If I were) a stranger, (I) just do what (I'm) trying to do. I've got to get in that mode with him too, because it may be a time where I really need to do something. And I'm trying to forget that this is my child, and just think about saving a life."

3.3.5 Little Access to Community Support

In the study, we saw a gap between community resources and people's access to them. During the participatory observation, we learned of several social systems to support families with asthma. For example, we attended asthma public seminars offered by healthcare providers. These seminars gave information and tips to manage asthma triggers in everyday lives. Also, we visited a free asthma screening service at a church, which taught how to diagnose asthma with portable medical devices. Additionally, we talked to social workers who participated in an asthma home visit service. This service particularly targeted the low-income families to diagnose and educate the householders about how to manage and prevent the triggers. They even offered complementary allergy-free blankets, pillows, and mattresses. Finally, we saw an active information exchange in online support groups. We joined two of them, and saw how families shared both medical information and their personal life stories.

Despite the available social support, we found that few families took advantage of them. In one of the seminars that we attended, the lecturers (three people) outnumbered the attendees (two people from our own research group). None of the caregivers

we interviewed told us that they registered with online support groups, attended any of these public seminars, and asked for the free home visit service. When we asked why they did not participate, they told us that they did not know of their existence. Instead, they heavily relied on healthcare providers as a resource for asthma-related information. However, we learned that other resources could benefit these families. In the study, we heard some evidence of how information from other sources could positively impact their asthma management. In P6's experience:

"My friend was one of the people that told me that my boy had asthma when the doctors said he did not and she would tell me to look into it or maybe I need to change doctors because she has asthma and she knows the symptoms and I did not know the symptoms."

3.4 Tool-Use and Technology Opportunities

This section discusses design opportunities emerging from our findings. I conceptualize these findings by superimposing the tools on the three main challenges: (1) detection, the difficulty of managing asthma triggers; (2) a behavior plan or treatment process; and (3) compliance, managing and sharing relevant data. Detection refers to recognizing asthma symptoms and triggers. It is the initial step for families to begin monitoring and controlling asthma. The second phase for asthma management is a behavior plan. During this phase, families set goals for behavioral modifications. After detecting asthma triggers, families plan to encourage their asthmatic children to alter behaviors to improve the status. Since children need help from healthcare providers and families, this phase is associated with collaboration with a doctor and the controlling strategies. The last phase is compliance. Here, healthcare providers try to understand if their asthmatic children are self-sufficient in managing their asthma. This compliance phase is related to documenting and controlling strategies for taking asthma medicines appropriately.

Table 3: Current tools to support pediatric asthma management phases.

Relevant phase (Strategies)	Tools	Main purposes	Advantages	Disadvantages	Opportunity
Detection (Monitoring)	TVs or Radios	Weather info. (e.g. rain, pollen, smog, grass), Medicine info.	Ubiquitous device, Easy of access because families always turn on TV for news	No mobility, Accessibility - hard to access information they want at the right time	Deliver relevant information to mobile device or computer via widget
	Internet (Desktop or Laptop)	Weather info., General asthma management information	Easy of access at office, home, library, Trigger alert in email	No personalized info., Accessibility - Need a computer, Reliability	Deliver relevant information to mobile device.
	Peak flow meter	Monitor a lung status	Mobility, Easy to handle	Recording, Accurate usage, Cleaning	Integrate capability to existing mobile device
	Mattress or Pillow cover	Avoid triggers (Dust)	Easy to use and manage	Cost, Cleaning	Smart fabric monitors irritants or Prospective reminders
	Air purifier	Improve air quality	Mobility, Easy to use	Cost, Maintenance, Reliability	Prospective reminder or Air quality sensor (ambient or individual) or Ambient Display
	Thermostat & HVAC	Keep appropriate temperature constant	Monitor and control temperature	No mobility, No control for outdoor air quality	Ambient display or smart appliance
A behavior plan (Controlling)	Vacuum cleaner	Remove and reduce asthma triggers	Maintaining good air quality, Easy to use	Child should not be present when it is used	Smart carpet; robotic vacuum avoid children, monitors carpet status
	Asthma action plan	Personalized guideline for ideal asthma management	Reliable information / Easy to understand	Information transfer, retrieval	Automated distribution list; active documents; SMS
	Medical documentation	Self-education and management	Easy to handle	Information retrieval	Bridging electronic document with physical artifact
	Asthma bags (or Medicine box)	Portable storage, Organizing various medicines	Mobility, Easy to handle, Personalization	Need to check everyday, Redundant medicines for several bags, Losing	See smart asthma bag discussion
Compliance (Controlling & Organizing)	Inhalers & spacers	Help asthma medicine reach to a child's lung	Mobility, Preparing several inhalers for asthma attack	Accurate usage, Cleaning	Instrument to monitor use
	Nebulizer	Help asthma medicine reach to a child's lung	Mobility, More effective than inhalers	Accurate usage, Cleaning, Need a plug	Smart material monitors irritants
	Mobile phone	Emergency contact, Reminder for schedule	Mobility, Accessibility, Text messages	No control for children's usage	SMS
All phases (Monitoring & Controlling)	Asthma diary	Personalized asthma information storage	Useful for remembering all info.	Hard to keep up all info.	Record tracking
	Note & Pen	Record symptoms & questions	Easy to use and access	Losing	Smart pen

I describe the tools that families reported using for asthma management and how they relate to the three components of the model. I present potential opportunities for technologies (see Table 3).

In the detection phase, families collect weather information from the TV. For example, H4 started watching a weather channel in order to obtain pollen information. I suggest that this information could be automatically sent to a mobile device or through the use of a widget on their home computer. In a behavior plan phase, parents must make the asthma action plan available to other caregivers. Its physical distribution can be a tedious process. An automated distribution list or an active file that maintains a log of the changes to the document would facilitate this effort. While many of the opportunities I present are hypothetical, I have evidence that technologies

can have a positive effect on asthma management as I discuss next. The study shows that parents employed both technical and nontechnical means to monitor asthma flare-ups. My analyses suggest that they utilized nontechnical means to monitor day-to-day symptoms and triggers. Families reported that based on past experiences they developed an intuitive sense for identifying asthma symptom precursors, which included observations such as a particular coughing sound or the heightened emotional state of their child. When the symptoms became more severe, they tended to rely on technical measures, such as a peak flow meter to monitor a child's lung capacity. Some caregivers used this peak flow meter on a day to confirm the self-reported symptoms from children.

My study with healthcare providers and community health workers suggests that technologies can help alleviate data sharing challenges. Families, healthcare providers and community health workers use mobile phones for pediatric asthma management [28]. This may be in the form of a call from the doctor's office to the parent to confirm that the asthma symptoms were controlled with a new dosage of medicine. Another idea is to provide a web-based dashboard where patient symptoms and important incidents (emergency room visits, rescue medicine taken) are logged either by direct entry (patient responds to an SMS message and confirms that he has been using rescue medication in an inappropriate manner) or by an automatic report that shows inappropriate usage of rescue medication. Initial findings from our health worker study suggest that they are willing to incorporate a dashboard into their practice [28].

3.5 Summary

I conducted interviews with pediatric asthma patients and their families, with healthcare providers and community health workers to investigate how technologies can help

improve asthma management. Based on the findings, I suggested design opportunities for technology to support pediatric asthma management that are based on three challenges: detection, a behavior plan, and compliance. My contributions are twofold. First, we identified user needs and challenges for asthma management. Second, we explore practical opportunities for technology interventions emerging from existing technologies in pediatric asthma management.

However, these design opportunities are heavily based on self-reports. To better understand the needs for technologies in pediatric asthma management, I felt the need to observe different stakeholders' technology usage in pediatric asthma management with currently available technologies. In the next chapter, I introduce the technology probes study that I deployed to gain lessons about how pediatric asthma patients and their caregivers actually use technologies for management, as well as design insights I gained for creating technologies dedicated to pediatric asthma management.

CHAPTER IV

ASTHMA MANAGEMENT PRACTICES FOR PEDIATRIC ASTHMA PATIENTS AND CAREGIVERS THROUGH IN-HOME TECHNOLOGY PROBES

In this chapter, I describe the development and deployment of technology probes [67] to understand how three pediatric asthma patients and their caregivers (Figure 4) adapted technologies to manage asthma to address the following research questions:

RQ2. Which characteristics of ubiquitous communication technology contributes to effective interventions for pediatric asthma management for children with asthma and their caregivers in a home setting, and how can we design them to improve pediatric asthma management?

The findings suggest that the severity of asthma can impact the way that technologies are utilized. Thus, technologies can assist families and pediatric patients by bridging gaps between users' needs and their practices, based on the severity of asthma and other contextual factors. This chapter describes the outline of the design of the technology probes and the results of the deployment study [161].

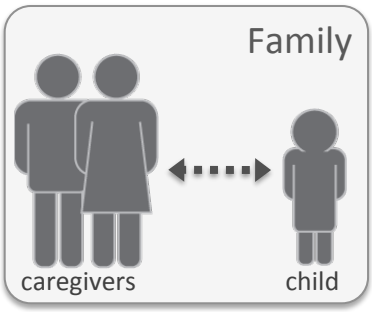


Figure 4: Users for Technology Probes.

4.1 Introduction

In this study, I seek to understand: 1) current asthma management practices; and 2) technology usage in pediatric asthma patients and their caregivers. I discuss the role that technology can have in a disease management model [28].

Addressing the research question above requires mixture research methods. Qualitative interviews of individuals with asthma and their caregivers, along with a technology probes study of actual technology use, can result in rich insight into current asthma management practices. To investigate health-reasoning strategies and context, I created and deployed technology probes. The technology probes in this study were prototypes of potential applications. The probes allowed users to track personally relevant aspects of everyday life by providing visualization tools to interpret the datasets they collect. Typically, applications that monitor the context of the onset of a chronic outburst could engage individuals and caregivers in reflective analysis [103]. Their goal was to minimize the onset of these outbursts by modifying the triggering behaviors. The probes in this study utilized sensing and self-reporting measurements to capture the patient's actions, daily trigger trends, symptoms, and daily peak flow meter readings [105].

The three main aspects of asthma management that emerged from the investigations are: 1) being an observer and engaging in judgments; 2) tractable management strategies based on the severity of asthma; and 3) the importance of reactions, namely the ability to make inferences about how to better manage asthma based on the data collected via the probes. I will discuss these aspects later.

4.2 Method

The research community has long realized the importance of an understanding of an individual's everyday life. Due to privacy and other sensitive issues of ethnography, a new set of techniques such as technology probes has emerged [67]. The goal of the

technology probe is to investigate the needs and desires of participants in a real-world setting and to test initial prototypes.

In this study, one of the main research goals was to use technology to understand how pediatric asthma patients and their caregivers reason in regard to the asthma symptoms and triggers. Thus, I designed several technology probes to provide context and engage families and pediatric patients in reasoning about their asthma symptoms, triggers, and perception. Here, technology probes were developed as a means of gathering information such as user requirements and needs [19]. The information I gathered was about understanding the real-world setting and potential new applications for pediatric asthma management.

4.2.1 Technology Probes

I designed the probes to support raising awareness of triggers (detection); the pediatric patient's health behavior (behavior plan); and other contexts in a reflective manner (compliance). The probes served as an early prototype of an asthma management system that allows users to record sensing data and daily activities. This was information that augments traditional asthma diaries. Our probes are described below. All components of the probe were from commercially available products except for the web based tool, Salud!, and a multifunction widget (see Figure 5).

4.2.1.1 Temporal Data Management Application

I provided participants with a web application called Salud!, an online system for tracking and reviewing everyday activities [108]. Participants were able to use Salud! to record and annotate events using a variety of methods. The data could then be reviewed and visualized using an online web application. The visualization tools included basic charts, graphs, and other summary views. Salud! came with a variety of event data templates (e.g., the measurement of peak flow, air quality index, meal times, and daily stress self-reports) that users could begin using immediately. I also

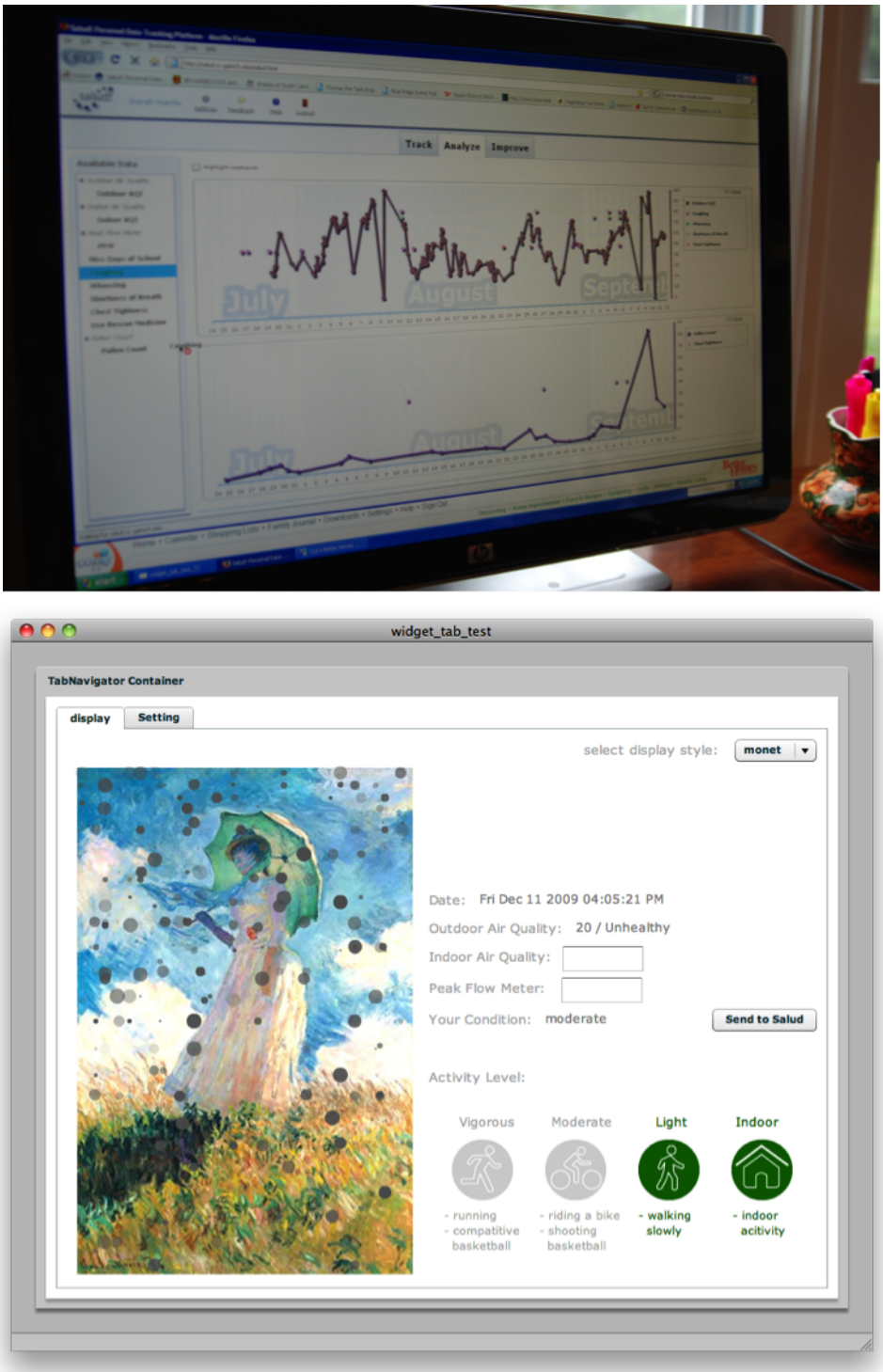


Figure 5: Salud! Application (Top) displays data collected from a variety of sources over the same period of time. This allows participants to reflect on the relationship between the data that is collected and their asthma status. Multifunction widget: Monet view (Bottom).

created a predefined set of logbooks for children with asthma. However, users were also able to define and create logbooks that they would like to track. Salud! relied on the user to input any information; it did not record any information without users' knowledge. Salud! did not present any automatically derived conclusions; nor did it make any recommendations to the users.

4.2.1.2 The Peak Flow Meter

I provided participants with a digital peak flow meter (Piko-1), and asked their caregiver to help manage the data from their child's peak flow readings. The children could also use a mobile phone's short message service (SMS) to enter the peak flow measurement into the Salud! application.

4.2.1.3 The Indoor Air Quality Sensor

I gave participants an air quality sensor (ET-4) to place in their home. This air quality sensor monitored indoor air quality (particulates) on a scale of 0 (good) to 1024 (bad). The unit measured many different airborne particles, such as pollen, dust and other air particulates.

4.2.1.4 Multifunction Widget

I implemented a widget that could be installed on their computer. The widget enabled users to look at outdoor air quality index based on a postal code of their home and recorded these values into Salud! every hour. A user could enter values of indoor air quality and peak flow meter derived from provided devices into the Salud! application via the widget. The widget showed appropriate physical activity level by adapting the Asthma Slide Rule, which provides practical guidance to parents in protecting "vulnerable" children during air pollution episodes [147]. The widget provides a straightforward means for determining acceptable physical activity levels based on outdoor air quality. The widget included two visualization modes. The first one was

Table 4: Demographics of Participants.

Participants (Ethnicity/Annual Income)	**Child's Asthma Severity**	**Participants** **Mother (Marital status, Age/Occupation / Education level)** **Child (Sex/Age)**
Family1 **(Caucasian/25,000~50,000)**	Moderate	Married/29/ Homemaker / College Girl (7)
Family2 **(African American/75,000~100,000)**	Mild	Married/34/Nurse / High School Girl (16)
Family3 **(African American/50,000~75,000)**	Intermittent	Married/43: Realtor / College) Boy (12)

a Monet view (see Figure 5, bottom), and another one was a Circle view. The number of moving circles in these views was correlated with the current harmful air quality in both views.

4.2.2 Deployment Study

Technology probes were deployed in three households for four to six weeks each. The participants for this study were recruited via recommendation of a physician and through Craigslist, a centralized network of online communities. Participants consisted of children with a clinical diagnosis of asthma, along with one of their parents (see Table 4). Participants were required to have regular access to a computer and Internet access.

Each of the participants, including children with asthma, was scheduled for an introductory 60-minute interview. During this meeting, we administered the consent form, conducted a semi-structured interview and assigned them an account on Salud!. We also provided them with a tutorial on how to use the peak flow meter, the air quality sensor information and various features of Salud!. However, we did

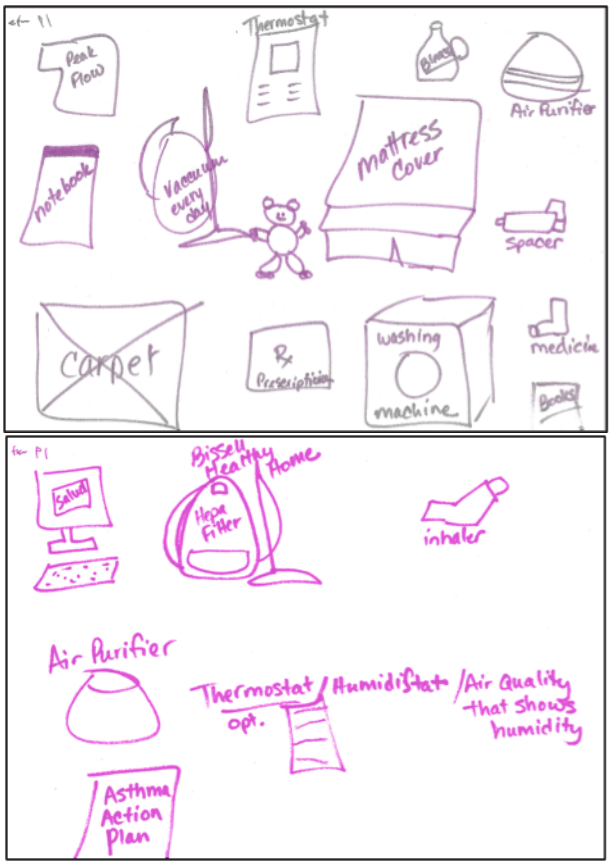


Figure 6: Participant's (Family 1- Mother) sketches (Top: before using the probes, Bottom: after using the probes).

not urge them to use the technologies we provided. We collected basic demographic information (gender, age, level of education, and occupation) and administered the Pediatric Asthma Quality of Life Questionnaire (PAQLQ), a well-established indicator of health-related quality of life [78]. Participants also drew a sketch with the various factors that impacted their asthma management. (see Figure 6)

During the study period, I conducted weekly follow-up interviews with the participants over the phone. The final interview occurred at the end of the deployment period in their home. All participants filled out a PAQLQ again. Additionally, I asked participants to reflect on the entire deployment period and to discuss any effects they perceived. In addition, I asked them to draw a sketch of their asthma management before (Top Figure 5) and after the study (Bottom Figure 5). This sketching activity

allowed for active involvement of the users in the very early stages of ideation and exploration. The approach provided a rich medium for discovery and communication of design ideas [144]. All the sessions were audio recorded, transcribed, and analyzed. I use pseudonyms for the participants in the case studies.

4.2.3 Understanding Current Asthma Management

Here, I report the effect that patient variables (e.g., age and asthma severity) and caretaker variables (e.g., occupation and income) have on asthma management.

4.2.3.1 Family 1 - moderate asthma

Susan is a 32-year-old homemaker with two children. Erika, the 7-year-old daughter, was in our study. Although Erika has a diagnosis of moderate asthma, Susan reports that the hardship of managing Erika's asthma led her to quit her job. Susan reported that Erika had been diagnosed as having a bronchial disorder by her pediatrician. However, over her life this condition became more severe, and it was in the last 3 months that the pediatric pulmonologist gave her a diagnosis of asthma.

Susan usually finds relevant information through the Mothers of Asthmatics website and a healthy home checklist from the website. Susan has tried to figure out what Erika's asthma triggers are. She thought that both allergies and physical activity caused Erika to experience asthma symptoms. However, Susan did not have specific examples from her environment to support her intuition.

Susan reported that the information she gathered related to potential asthma triggers made her change her lifestyle. One of the things that Susan changed after having been to the pulmonologist was her housekeeping practice. She stopped cleaning with commercial cleaners. Now she cleans with baking soda and vinegar. She washes everything in hot water. She vacuums all of the furniture once a week and vacuums the carpet twice a week. To reduce allergens, Susan bought an air purifier that her pulmonologist recommended. However, she was not confident that this was helpful.

Susan noted that the work load associated with managing Erika's asthma was intense and that she did not think she would be able to maintain it if she was working. Susan had been concerned about Erika's school environment. She noted that cockroaches are an issue because Erika was allergic to them. Susan thought that she could control domestic environmental factors as well as behavior that negatively affect Erika's asthma status (i.e. dust, dirty carpet, germs). However, she did not feel the same was true when Erica was at school. For example, she noted that she could not control what Erika did during recess.

Susan had taken a systematic approach to managing her daughter's asthma. She reported that she would write down a given goal and then she would write down the steps that she needed to take in order to meet the goal. Susan was using a web-based journal and Excel to do this and share with their doctor.

4.2.3.2 Family 2 - mild Asthma

The second participant, Julie, was a 34-year-old nurse. Her 16-year-old daughter, Monica, was only diagnosed eight months prior to the study.

Monica's asthma was mild. However, because of the recent diagnosis, they were still trying to find possible triggers. Julie gathered information about asthma through online sources. Julie had nutritional books that she used as references to manage Monica's asthma. Since Julie was working for a doctor's office, she also collected information from her colleagues.

Julie tried to manage Monica's asthma with diet and supplements (not medication) through trial and error. For example, early on they suspected ice cream as one potential trigger but since then they had realized it did not really impact Monica. They had an air purifier in Monica's room since they thought indoor air quality was important for Monica's symptoms. Julie reported that her ability to manage Monica's asthma was sometimes impeded by her job. She sometimes had to work nights

and thus could not manage Monica's diet.

Monica was an adolescent that took charge of monitoring her asthma status. Monica was knowledgeable about her symptoms and triggers and read books related to asthma. However, Monica sometimes did not like to share her asthma status with her mother because Monica did not want her mother to *"nag"* her. She wanted to be independent.

4.2.3.3 Family 3 - intermittent asthma

The third participant, Natalie, was a 43-year-old realtor. She usually worked at home on the computer. Her 12-year-old son, Mike, has asthma. He was diagnosed as a 3-year-old.

Mike's asthma was under control, and he only had intermittent flare ups. Due to the status of Mike's asthma, Natalie spent much less effort in managing her child's asthma than the other participants. She typically focused on medication and did not pay attention to possible triggers (i.e., environmental factors). Like Monica, Mike was knowledgeable about his symptoms and triggers and was in charge of taking his medication when required.

4.3 Findings

In this section, I will discuss the interview findings. I will also provide analyses of probe deployment case studies to address current asthma management practices and technology usage.

4.3.1 Understanding Technology Usage

The technology usage among the three families varied. The use of the probes increased their observations and influenced their judgments and reactions.

4.3.1.1 Family 1 - moderate asthma

Susan used the probes continuously during the deployment period. She created an additional logbook in Salud! to record pollen counts since Erika had pollen allergies as well. Susan encouraged Erika to use the peak flow meter at least twice a day. Susan put the indoor air quality sensor near the desktop in the living room. Whenever Susan used her desktop, she checked the widget to find out outdoor air quality and the indoor air quality. Since Susan already kept family records in an online journal, she felt that using a computer to enter data was not overly demanding.

Based on the measurements of the peak flow meter, Susan tried to find out which triggers affect Erika's symptoms. The data collection led her to believe that outdoor air quality affected Erika's status. However, she could not find any other correlations. She even created the pollen counts logbook. In terms of the indoor air quality probe, she found the sensor was not sensitive enough to register immediate changes in the environment. Thus, she could not determine what caused the change of indoor air quality measures.

After using the probes, Susan discovered that outdoor air quality was an asthma trigger. She then tried to reduce Erika's physical activity when she saw high index of bad outdoor air quality. Although the indoor air quality sensor was not sensitive enough to detect major changes in the indoor environment, Susan opened windows when she cooked or vacuumed.

Susan enjoyed Salud! so much that she decided to keep records in Salud! even after the deployment ended, and Erika was back in school. However, tracking Erika's symptoms was much more difficult than it had been during the summer because Erika did not tell her mother everything she did in school. Interestingly, Susan's drive to collect data in Salud! led her to conversations with Erika that indicated that physical exercise exacerbated Erika's asthma symptoms (i.e., her symptoms were worse on days that she had gym).

4.3.1.2 Family 2 - mild asthma

For the deployment, we asked Julie to install the widget. However, Julie did not want any desktop application installed on her computer because of privacy concerns. Julie agreed to access Salud! since she thought Salud! was safe because it was a web-based application.

During the deployment, Julie thought that her daughter Monica could take care of herself and so chose not to use any of the system's features other than the air quality sensor. Thus, Julie did not know how many symptoms Monica had and what Monica found in terms of triggers. Monica, on the other hand, was involved with the system. Even though we did not provide the widget, Monica accessed a web page that showed outdoor air quality and recorded these values in Salud!. Despite her mother's objections, Monica wanted the widget because it was tedious to access the web page to have information whenever she used Salud!.

By using the system, Monica was able to dispel her belief that indoor and outdoor air quality negatively impacted her asthma status. She also noted that she actually became more aware of her symptoms because she could record all her symptoms (see Figure 7).

Julie reported that she was happy with the system since she could persuade Monica to do the right things based on the values Monica entered. She told us that one of the advantages of the probes was that it helped her visualize things that would have otherwise been invisible. For example, the peak flow meter informed the status of Monica's lungs. Similarly, the air quality sensor provided them with the data they could not ascertain by looking out the window.

They did not report any disadvantages in using the technology. They thought more information always worked better unless the data were false.

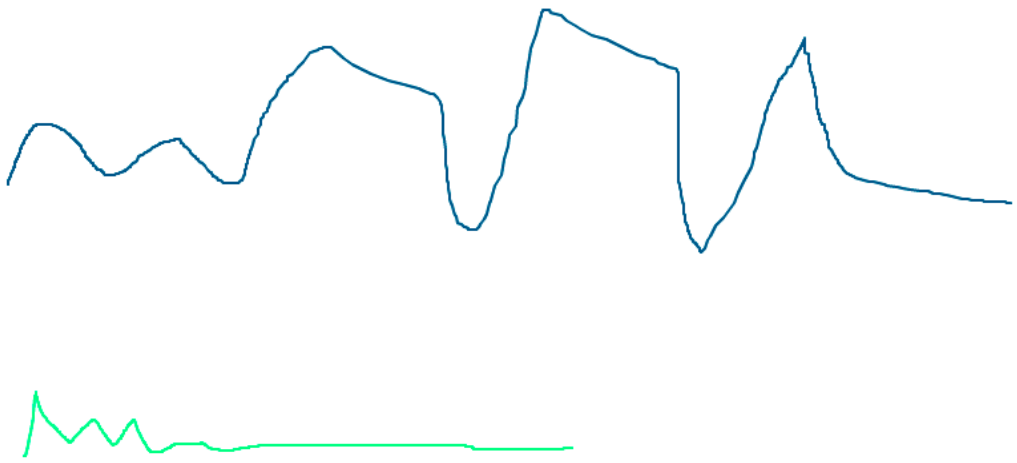


Figure 7: Participant's (Family 2- Child) sketches (Top: before using the probes, Bottom: after using the probes).

4.3.1.3 Family 3 - intermittent asthma

Natalie minimally incorporated the technology. For example, she did not try to find any relationships between triggers and symptoms because Mike did not have any flare-ups during the deployment period. She did not change her lifestyle much. In the first few days of the study, she recorded peak flow meter and indoor air quality measurements. After that, she did not use Salud! and the peak flow meter anymore. However, she was still looking at the indoor air quality sensor and the widget when she started working at home. She said that she was still generally concerned about whether he was taking the medication properly. After the study, she wanted to keep the indoor air quality sensor to manage her house's air quality (see Figure 8).

In sum, three households showed a range of technology incorporation. It seems that the severity of asthma influenced the degree of technology utilization. But overall, all householders noted the improved quality of life and the perceived benefit of the technology. According to the sketching activity, Family 1 reduced the number of factors they had to manage. Family 2 reported that their asthma management became

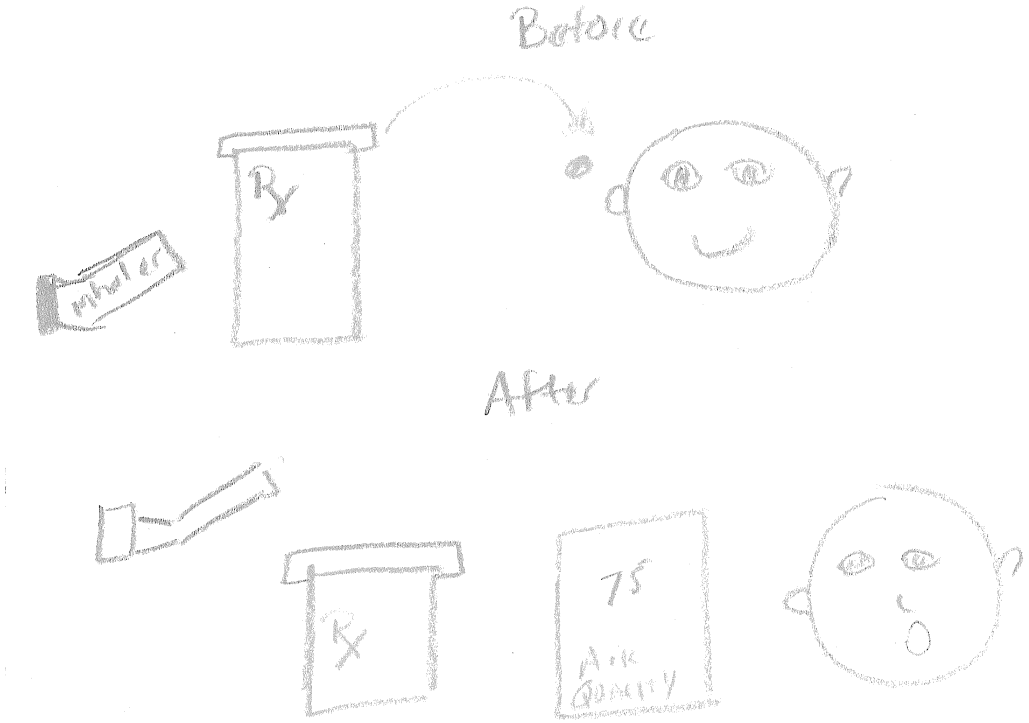


Figure 8: Participant's (Family 3- Mother) sketches (Top: before using the probes, Bottom: after using the probes).

Table 5: The number of recorded logbooks.

	Participant (The number of days of deployment)		
Logbooks	***Family1 (44)***	***Family2 (28)***	***Family3 (32)***
Chest Tightness	4	0	0
Coughing	12	3	0
Indoor Air Qaulity	73	11	3
Miss Days of School	0	0	1
Outdoor Air Quality	465	9 (Manual)	190
Peak Flow Meter	62	11	2
Shortness of Breath	7	0	0
Use Rescue Medicine	5	0	0
Wheezing	0	3	0
Pollen Count	26	N/A	N/A
Total logs per day	**15.86**	**.84**	**4.45**
Manual logs per day	**4.30**	**.84**	**.14**

more constantly coordinated after having the probes. Table 5 shows the number of recorded logbooks during the deployment. Once again, severity of asthma impacted the data we found. Family 1, who had the most severe asthma status entered more logbooks in an attempt to find the relationship between triggers and symptoms. The last family was symptom free and did not use Salud! at all.

All participants reported an improved quality of life after using the probes. This is interesting given that 2 of the 3 families only used the probes on a limited basis. Data indicated that the severity level of the child's asthma had a large impact on the quality of life of the family. Family 1 reported the lowest PAQLQ score and had the most severe case of asthma. The other two families reported similarly high PAQLQ scores at both pre and post visits.

4.4 Discussion

In this section, I will outline the main findings and how they relate to different aspects of asthma management of my previous study in Chapter 3.

4.4.1 Emerging Aspects of Asthma Management

4.4.1.1 Being an Observer, Engaging in Judgments, and Communicating with Healthcare Providers

The main goal of all asthma management activities is to reduce symptoms and avoid hospitalization. The management techniques, which are related to compliance, usually include taking appropriate medications at appropriate times and avoiding triggers. While the NHLBI Guidelines for the Diagnosis and Management of Asthma provide regimens [113], developing a customized management strategy is still a challenge for families and pediatric patients with asthma.

Due to the heterogeneity of asthma, healthcare providers have difficulty providing detailed guidelines concerning the triggers that impact the individual. Thus, families and individuals with asthma need to proactively analyze the relationships between contexts and outbursts, and need to communicate with their healthcare providers to obtain additional information.

4.4.1.2 Tractable Management Strategies based on the severity of asthma

Families and newly diagnosed pediatric patients have a hard time figuring out which triggers affect their asthma. It takes time to establish strategies for asthma management. However, it is critical to find triggers as soon as possible because even a single episode can lead to the patient's death.

According to NHLBI guidelines, physicians adjust patients' therapies based on the severity of the condition. Similarly, intervening technologies should actively adjust to the evolving severity of the condition for each patient to support a behavior plan.

4.4.1.3 Importance of Reactions

All participants tried to reduce or avoid triggers. For example, cleaning their homes frequently, using alternatives to chemical cleaners, and changing physical activities were among the most common actions reported by our participants.

However, unlike other chronic conditions, many critical asthma triggers are typically outside the control of the patient, for instance, pollen count and pollution. This difficulty of asthma management often results in patients ignoring triggers, ultimately leading to a complete abandonment of their asthma regimen. Thus, technology can provide information about triggers and allow individuals to make observations and judgments that lead to appropriate reactions. Reactions include a parent's confidence level related to preventing his or her child from getting triggers and symptoms, and how parents know specific disease management strategies to control triggers and symptoms.

4.4.2 How can technology assist individuals in managing their asthma?

The severity of asthma impacts observations, judgments, and reactions. If pediatric patients have a mild or intermittent condition, they might not need to make observation frequently, and there are no triggers to monitor regularly. However, they still need a place to register their observations to prevent exacerbations. Technology can facilitate these goals and, for example, provide reminders to take medication, or it may provide a way to support judgments and reactions via record tracking technology that can later be *"mined"* to find low frequency triggers (i.e., seasonal asthma attacks).

Severe and moderate conditions imply that patients would experience symptoms almost every day. Technology can be especially helpful in this context. The emerging sensor networks and the effeorts of citizen science can help individuals keep track of triggers that might affect symptoms [8]. However, the communication gap between

parents, children, and healthcare providers can negatively impact the accuracy of observations and delay in treating symptoms. Thus, a capture and access service and a communication tool can bridge this gap and help to treat symptoms. For example, in this technology probe study I found that the temporal data management application helped one family identify relevant observations. Here, the parent was able to map an external context (e.g., school schedule) and activity (e.g., physical exercise) to an increase in asthma symptoms.

Data logging activity itself can raise the awareness of symptoms. For example, one of the pediatric participants reported that using the probes helped her realize that in the past she was actually ignoring her symptoms. She reported that once she became aware of her symptoms (because of data entry into Salud!) she was more motivated to take her supplements.

4.4.3 What is the necessary and sufficient level of technological support to provide an adequate management solution?

Reaching patients' management goals is important; however, we should consider a balance against participant's perceptions, technologies' inconvenience and costs.

First, we should consider privacy issues in developing applications. This is not only about data security but also how users perceive security. For example, one of the parents did not allow us to install the widget because she did not trust it. She placed a higher value on web applications even though there is no difference, in terms of intrusiveness, between desktop-based and web-based applications. Thus, we should be careful in deciding on what platforms we choose to implement our applications.

Second, caregivers and patients with intermittent and mild asthma conditions might not use novel interventions. This would negate the need to develop technologies for data that is readily available online i.e., air quality and pollen counts.

Third, we should not overrate existing technologies. For example, I built in a feature that allowed individuals to use their mobile phone to enter data into our

system. However, no participants in our study used this feature. This was the case because two children did not have their own phones and the other did not use the peak flow meter because he did not have any problem. However, it does not mean mobile technology is useless. Thus, we should investigate and understand the target population's practices before introducing and designing technological features.

4.5 Summary

In this study, I explored opportunities to improve asthma management by deploying technology probes. This study described the need for pediatric asthma patients and caregivers to observe and engage in judgments to control their asthma symptoms and triggers. Understanding the consequences of context allows tractable management that leads to changes in confidence levels and sense of control.

My findings highlight a number of possible opportunities for improving pediatric asthma management by technologies. However, the limitation of this study was focusing on only pediatric asthma patients and their caregivers. As I described in chapter 3, technologies could help alleviate asthma data sharing challenges between healthcare providers and pediatric patients for asthma management.

Based on my current findings, the role of healthcare providers should be considered in designing technology that has features supporting children's asthma knowledge, symptoms, and their contextual information regarding asthma. In the next chapter, I will describe a hypothesis driven study that investigates the role of a mobile and web service to support communication between pediatric patients and healthcare providers.

CHAPTER V

THE SMS SERVICE AND PHYSICIAN'S DASHBOARD DESIGN

My previous work had grounded my understanding of pediatric asthma management and how pediatric asthma patients and their caregivers appropriate technologies. My next step was to use a mobile and web service to deepen my understanding of pediatric asthma management–not only between pediatric asthma patients and caregivers (Chapters 3 and 4) but also between pediatric asthma patients and physicians. As Figure 9 reveals, the ecology surrounding a child with asthma involves a number of communication channels between a family and a doctor's office, some of which my technology explicitly supports, and others which it supports only implicitly.

Effective communication between patients with chronic conditions and health professionals positively influences chronic health care, as does increased patient awareness of their symptoms and general knowledge of the condition. In this chapter, I describe the approach I took in exploring design ideas.

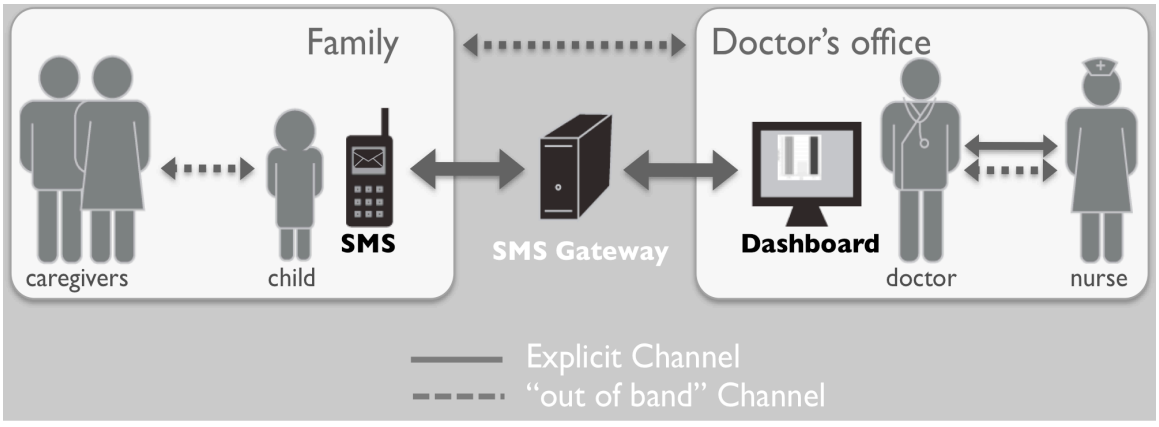


Figure 9: SMS/Physician's Dashboard system architecture.

5.1 Backgrounds and Motivation

The major takeaway of the results from Chapter 3 and 4 in supporting pediatric asthma management is information sharing through communication between the different stakeholders. Pediatric patients that have moderate to severe asthma regularly visit their doctors every 3 to 4 months. Despite the knowledge that information sharing is crucial, communication between the patient and physician between these visits rarely happens unless there has been a serious episode such as the emergency room visit according to our observations [122].

There is a new sense of hope for managing chronic health conditions because of another increasing trend, the adoption of mobile phones and text messaging. There are billions of mobile phones exchanging tens of billions of text/SMS messages daily, meaning that it is increasingly likely that a child living with asthma can have access to SMS [99]. This observation leads us to ask whether the child's mobile phone use can be leveraged to support asthma management. I present results from an initial empirical study aimed at answering that question.

Several known factors influence the effective management of a chronic condition, including: open communication between patients and health care providers [22, 24]; a patient's awareness of symptoms and knowledge of her/his condition [130]; and the level of adherence to medical regimens [148]. Effective communication may be as valuable as proper medication choice in the long-term success of asthma control [22].

To facilitate the effective communication, some questionnaires such as the Asthma Therapy Assessment Questionnaire (ATAQ) were developed to assist physicians in identifying children at risk [138]. However, these questionnaires are only administrated when pediatric patients visit their doctors and not all doctors use them. I chose SMS on the pediatric patient's mobile phone because of the high adoption rates within the teen/youth population. A survey showed that one-third of teenager sends more than 100 text messages a day [99]. I used simple email alerts and a web-based

visualization for the physicians, based on our observations of their work practices [122].

In this chapter, I present the design of a system that leverages SMS messaging to facilitate continuous communication between a child with asthma and a physician who treats that child based on the Health Belief Model (HBM) [130] and findings in prior studies [122]. The Health Belief Model (HBM) provides a valuable theoretical underpinning to explain the role of the perceived severity of disease as *"individual beliefs"* and knowledge acquisition as *"modifying factors"* that influence the management of chronic illness (see Figure 2 on page 15). Responses to the SMS queries were fed into a web-based visualization tool for the physician.

5.2 Method

In order to address the identified issues above, I designed a SMS service and a web service to facilitate constant communication between a pediatric asthma patient and a physician who treats that child. Regular responses to SMS queries about a child's asthma symptoms and self management were feed into a web-based visualization tool for the physician. My system was designed to address the following research question and hypotheses (below):

RQ3. How do pediatric asthma patients and healthcare providers adopt a mobile and web service over the course of several months to improve asthma knowledge and awareness, and to affect the perceived quality of interaction with the healthcare providers[1]*, which can lead to improved quality of life and health outcomes?*

H1: Pediatric asthma patients answering regularly-administered questions about their asthma management via SMS will demonstrate better health outcomes than a control group of asthma patients, as measured both by a quality of life questionnaire and a pulmonary function test.

[1] *the perceived quality of interaction was measured in Chapter 6*

H2: Pediatric asthma patients answering regularly-administered questions about their asthma management via SMS and receiving regularly-administered information via SMS intended to increase their knowledge about asthma will demonstrate better health outcomes, as measured both by a quality of life questionnaire and a pulmonary function test, compared to those receiving only regularly-administered SMS questions and controls.

H3: The "rolling ATAQ" score calculated by the answers of the SMS queries will provide continuous assessments of pediatric asthma management when compared to the original ATAQ score.

5.3 System Design

Our observation and survey show that the technologies used by the physicians included laptops, mobile phones, and pagers [122]. The laptops were connected to the internal network and linked to the clinics Electronic Medical Record(EMR) system. All physicians used the laptop mostly to view or type notes into the EMR system. All the physicians had Blackberries, but their usage patterns differed. Email was most often viewed on the Blackberry.

Initial meetings took place with researchers from Georgia Tech and members of a research team from a private practice, which is the largest private pediatric pulmonology practice in the United States. The potential of using a SMS service and a web service as part of the pediatric asthma management was discussed prior to the design process. The idea of using text messaging and a web service as a communication tool for pediatric asthma patients and healthcare providers was met with positive reactions.

To increase the feasibility of SMS as a mean of delivering knowledge and asthma symptom/management questions to a large number of children, the SMS service

should deliver automated and scheduled text messages, and retrieve patients' responses. We identified a broad set of design requirements during an initial brainstorming design session. The physicians began by defining the requirements that they expected the services should offer. We expanded and refined these requirements to exchange emerging ideas within the design team, and then built paper-based prototypes to visualize the web service and discuss the requirements. The main requirements we gathered included:

1. Text messages should be easily understood, as the pediatric asthma patients would use their mobile phones on a regular basis.

2. Text messages should be based on existing and validated questionnaires.

3. The SMS service should manage the delivery and retrieval of text messages.

4. The physicians should easily understand the interface of the web service, as they would use the system on an irregular basis. The purpose of using the Physician's dashboard was to minimize the burden for regular interaction. Once the physicians received alert emails, they would be able to manage individual patients with the minimum of effort.

5. The SMS service should manage the responses from the patients.

6. The services would be validated in a clinical trial, and therefore needed to produce a number of measurable results (e.g. the number of messages sent to and from each patient and physician, the number of logins, the number of alerts) for analysis.

7. The services should be robust during a full trial without failure.

With the assistance of two pulmonologists, our team designed a system with two parts: 1) an SMS service as an asthma survey and education tool for children with

asthma; and 2) a Physician's dashboard as an interface to review patients' status (the web-based visualization tool). The system explicitly supports the communication between the patient and physician and between the physician and other clinical support staff (e.g., a nurse), while it implicitly supports the "out of band" communication between the parents or other caregivers as well as between the doctor's office and the family.

5.3.1 The SMS Service

The SMS service sends questions about asthma management and questions about asthma knowledge directly to pediatric patients in a predetermined fashion. The patient decided what time of the day he or she would like to receive the queries. For questions about asthma management, two physicians and I developed SMS-formatted questions based on a standard instrument used during doctor visits, the Asthma Therapy Assessment Questionnaire (ATAQ) [138]. The physicians helped me to modify the ATAQ question and to produce other important questions that were not in the ATAQ itself. This required careful rewording of the questions to be age-appropriate and clear. Figure 10 shows the example of an asthma symptom/management query.

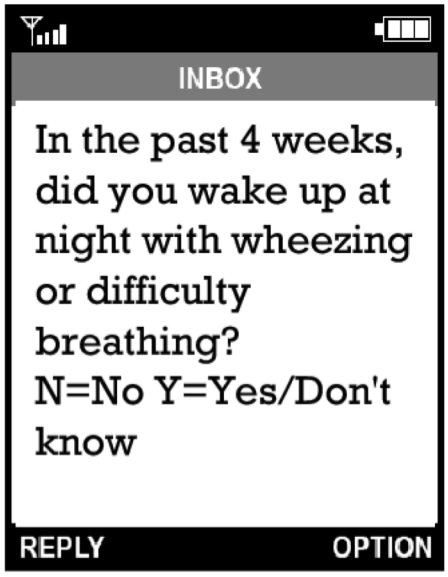


Figure 10: Example of SMS symptom/management query.

In addition, SMS-formatted asthma knowledge questions were formulated. The child was asked to answer the question, and was sent the right answer regardless of his or her response. The SMS server was instrumented so that I could monitor the response rates of the participants. Figure 11 shows the example of an asthma knowledge query and response.

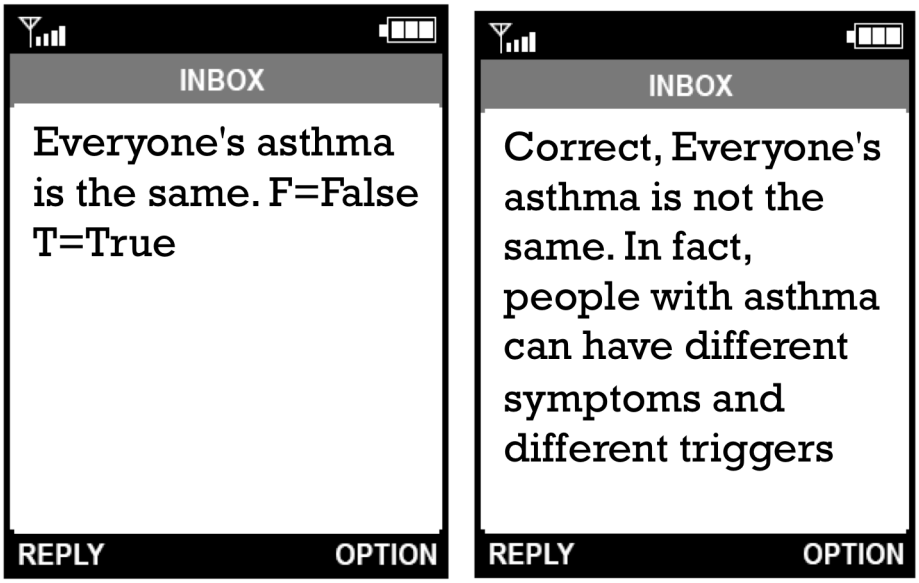


Figure 11: Example of SMS knowledge query and response.

I built two versions of the SMS service for the study: a query version and a query and knowledge version. Patients were randomly assigned to either one of these groups or to a third control group that received no SMS messages. Next, I describe each version.

Query version

In the query version, one of fifteen yes/no questions about the patient's asthma symptom/management is sent out every other day (see Figure 12). Patients' response data is visualized in the Physician's dashboard, described below. If a patient answers a question with 'yes', the SMS system adds an 1-point to the "rolling ATAQ" score (the range of the "rolling ATAQ" score is from 0 to 15). After the SMS system has received the first fifteenth answer, the "rolling ATAQ" score is applied to the Physician's dashboard at that day. Afterward, whenever the SMS system receives a new answer, the "rolling ATAQ" score is updated with recent fifteen answers (see Appendix F). One the other note, each question is given a weight ranging from 0 to 3. (e.g., taking rescue medicine (2 points)). If a patient answers a questions with 'yes', the SMS system adds an assigned weight to the "Zone" score, which is different from

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
Q1		Q2		Q3		Q4
	Q5		Q6		Q7	
Q8		Q9		Q10		Q11
	Q12		Q13		Q14	
Q15		Q1		Q2		Q3

Figure 12: Schedule of SMS symptom/management query.

the "rolling ATAQ" score since some questions have zero weight. After patients have responded to the first fifteen questions, the system calculates the "Zone" score, which is the sum of the weights for a recent fifteen answers. This score categorizes patients into three zones: Red: needs attention soon (a score of 3+), Yellow: might need attention eventually (1-2 points), and Green: OK (0 point). In addition, there are questions that indicate that the patient may be in trouble or headed for trouble, and so the system automatically categorizes the patient into the Red zone. I collaborated with physicians to develop this scoring and classification scheme (see Appendix A).

Query and knowledge version

The query and knowledge version is the same as the query version with the addition of fifteen true/false questions about general asthma knowledge that are administered on days that they do not receive queries (e.g., Asthma is a psychological condition. F=False T=True) (see Figure 13). The system separately calculates the "rolling ATAQ" scores and the "rolling knowledge" scores. If a patient answers the correct answer to a knowledge question, the SMS system adds an 1-point to the "rolling knowledge" score. After the SMS system has received the first fifteenth answer, the "rolling knowledge" score is applied to the Physician's dashboard at that

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
Q1	K1	Q2	K2	Q3	K3	Q4
K4	Q5	K5	Q6	K6	Q7	K7
Q8	K8	Q9	K9	Q10	K10	Q11
K11	Q12	K12	Q13	K13	Q14	K14
Q15	K15	Q1	K1	Q2	K2	Q3

Figure 13: Schedule of SMS knowledge query.

day. Afterward, whenever the SMS system receives a new answer, the "rolling knowledge" score is updated with recent fifteen answers. In order to increase the patient's knowledge about asthma, patients are told whether they answered the question correctly or not and then given information related to the specific question. The patients' responses to the knowledge questions are aggregated in the Physician's dashboard.

User Interaction

The layout of text message screens varies based on the specific mobile phone's text messaging capabilities. When a user receives a message, she/he can reply to the message by just entering 'y'/'n' or 't'/'f'. The system allows other answers such as 'yes'/'no' or 'true'/'false'. However, if the response is something else, the system does not count up the response for the rolling scores. For knowledge questions, the SMS service sends correct information regardless of the patient's answer.

5.3.2 Physician's Dashboard

In designing the web service for Physician's dashboard, we needed to optimize the design of the web service to fit into the work practices for the pulmonologist. Using health informatics software is usually difficult and needs training [162, 94]. Healthcare providers in the private practice are using the similar complex software in their

practice.

Thus, the web service should be designed for primary users, pulmonologists, who might not have advanced computing experience. They also do not have enough time to take a training class, so it muse be clear how to use it from the first encounter with a simple manual (see Appendix C).

To design the Physician's Dashboard, I used a paper-prototype. The purpose of building a paper-prototype is to provide a model of the web interface so that the end-user can provide feedback, and to let designers refine the interface [39]. We made a total of three prototypes during the design process. The first prototype was a paper-based prototype, while the second and final prototype were an almost complete version of the web service.

The paper-based prototype led to the development of the second electronic prototype since we found that the Physician's dashboard should alert pulmonologist via email when a patient has an issue.

The second prototype was created in HTML and JavaScript to allow physicians to see approximately how the Physician's dashboard would work. Following with the participatory design process [91], I encouraged the physicians and researchers to assess the prototype by performing a sequence of tasks. I used 'think-aloud' to 1) identify errors in the design of the Physician's dashboard 2) refine existing requirements, and 3) identify additional requirements [117].

The think-aloud technique identified the problems that a lot of texts on screen hindered the physicians from understanding what happened at a glance. Additionally, there was no way to track patients' status in the prototype. Figure 14 shows the screen shots the physicians can have access to patients' responses.

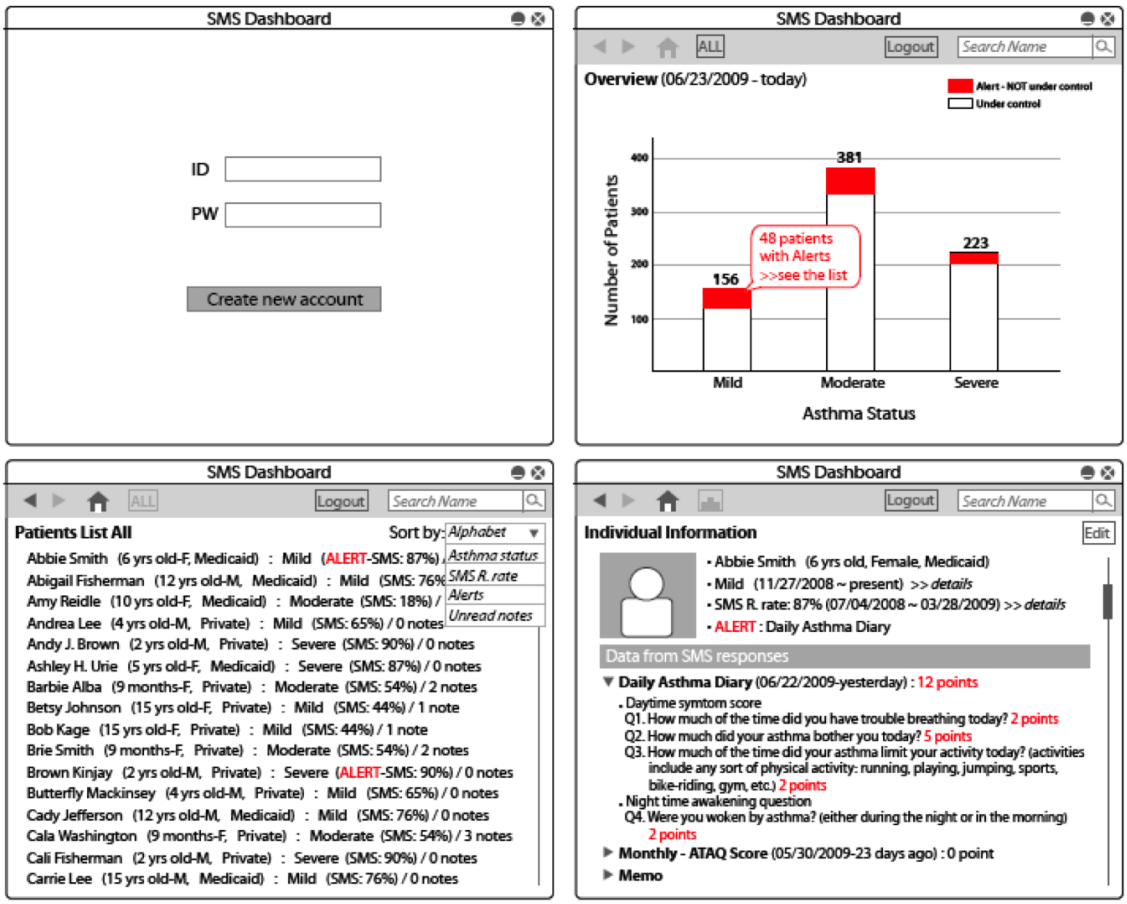


Figure 14: Physician's Dashboard Prototype.

The final iteration adopted three screens: 1) the "zone" screen; 2) patients' list screen; and 3) the "rolling" score screen (see Figure 15). As noted above the Physician's dashboard is populated with the physician's patients' SMS responses. This allows physicians to monitor patients' status and to interact with their care team for administrating care outside of the doctor's office. The web service helps to highlight patients in at least three different zones (Red: needs attention soon, Yellow: might need attention eventually, and Green: OK).

This Physician's dashboard contains all of the relevant care information for each patient in the study, including summaries of asthma status, knowledge based on patient responses to the SMS-facilitated surveys, and relevant identification information to link to the electronic medical record system used in the doctor's office. Occasionally, the physician would be sent email alerts to encourage them to view the Physician's dashboard. There are two situations that would trigger the sending of such an alerting email. The first situation is when a patient answers, "yes" to any of a set of specific questions (each such question had a weight of 2 or 3; e.g., questions about taking rescue medicine, emergency room visits, taking an oral steroid, and hospitalization (see Appendix A). This is intended to inform the physician that one of their patients has entered the Red Zone and may need immediate attention (see Figure 16). The second alert is sent whenever a patient responses to the last one in the set of symptom/management, which would happen every 50 days, assuming the child is responding to all symptom/management queries. If the children is not responding, the SMS system does not send the second alert. These alerts are intended to remind the physician to review information on this child.

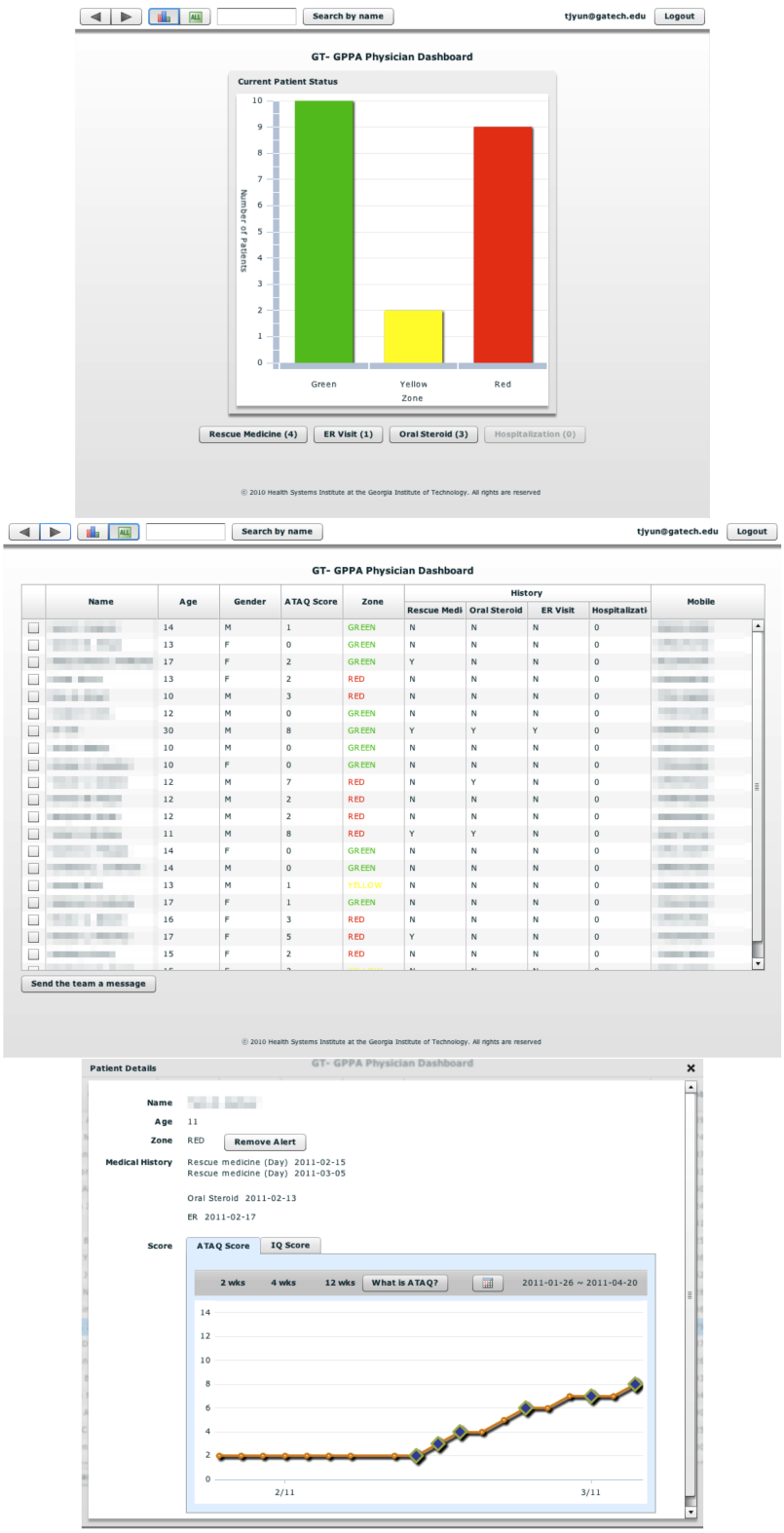


Figure 15: The Physician's dashboard Screens (top: the 'zone' screen, middle: patients' list screen, bottom: the "rolling" score screen).

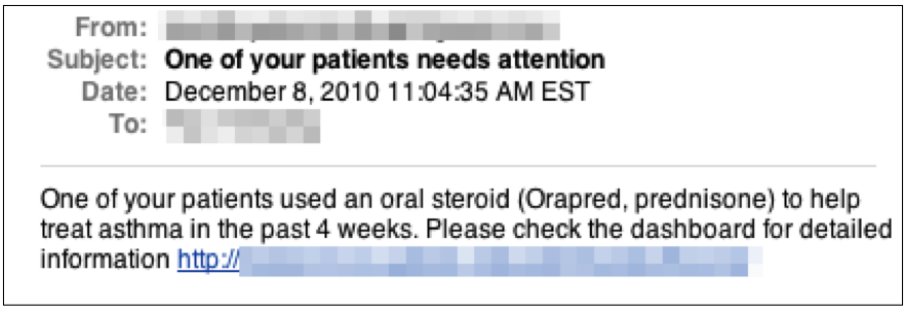


Figure 16: Email Alert.

If, for any reason, a physician is concerned about the status of a patient when viewing his or her detailed information in the Physician's dashboard, an email can be sent to that physician's nurse directly from the Physician's dashboard. The email contains some template information about the patient and the physician can tailor the message to indicate any particular actions the nurse should do as follow up (see Figure 17). Our system logs this email behavior as well, as a record of physician-to-nurse communication driven by the Physician's dashboard.

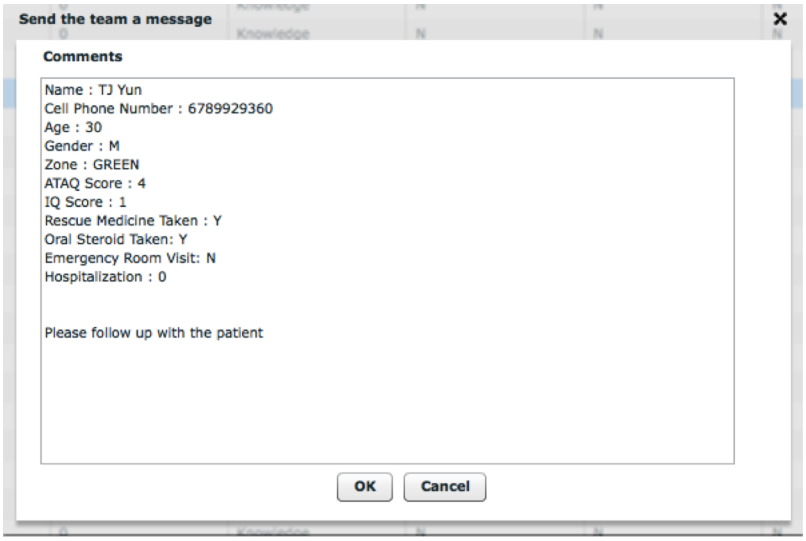


Figure 17: Email template.

5.4 Conclusion

Our exploration of the needs and requirements of patient-physician communication resulted in the SMS service and Physician's Dashboard. Researchers and pulmonologist designed the system. Doctors saw opportunities for using the Physician's Dashboard for pediatric asthma management. Our design process provided early answers to key feasibility of the system and helped modify directions for design. A clear next step became conducting a filed deployment of this system in the clinical setting for pediatric asthma patients and their pulmonologists. I will cover two deployment studies in the next chapter.

CHAPTER VI

THE FIELD DEPLOYMENT OF THE SMS SERVICE AND THE PHSYCIAN'S DASHBOARD

In this chapter, I present the two filed deployment studies of the SMS service and Physician's Dashboard. I investigated results from a randomized controlled trial (RCT). I examined: 1) how an SMS system impacted the health outcomes of asthmatic children; and 2) how physicians used a web service showing the data gathered from the SMS system.

I will describe the details of the SMS-based communication system I developed and evaluated in a controlled study of total 65 (first deployment: 23, second deployment: 42) children all being treated by the same pediatric pulmonology. I designed the study to explore our technology intervention during the period between two scheduled visits to the pulmonologist. I analyzed the data I collected to address the direct and indirect health benefits. I discuss my findings in light of research indicating that a very interesting, yet poorly understood facet of chronic care is the way healthcare providers and patients communicate with each other [86, 85]. My research addresses this issue directly.

6.1 First Deployment

In this section, I describe the details of the first deployment study. Physicians and pediatric asthma patients were enrolled in the study during the period between two office visits (usually for around three or four months).

6.1.1 Measures and Instruments

I used the following measures to test the previously state hypotheses: asthma knowledge, quality of life, asthma therapy assessment questionnaire, and pulmonary function. We developed surveys and interview questionnaires, and used already validated quality of life questionnaires [79, 80] and asthma therapy assessment questionnaire [138].

Asthma Management Practice and Demographics

I obtained basic demographic data, technology usage, and current asthma management practices by administrating our survey forms for pediatric patients and caregivers (see Appendix D). Pediatric patients and their primary caregivers completed their own surveys.

Asthma Knowledge

Since no validated asthma knowledge questionnaires exist [90], we developed the questionnaire for use in my study to learn what pediatric patients know about asthma. Knowledge was measured using a 15-item true and false questionnaire, adapted existing asthma myth questionnaire from *Medicinenet.com*, with input from two pulmonologists. However, we did not evaluate the reliability and validity of the questionnaire.

Quality of life

I used validated questionnaires to assess pediatric patients' and primary caregivers' quality of life. The Pediatric Asthma Quality of Life Questionnaire (PAQLQ) [79] and the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) [80] use 7-point Likert-scales. Juniper validated the questionnaires among 52 7- to 17-year-old children and their primary caregivers. In those studies, the PAQLQ and the PACQLQ were able to detect quality of life changes in those patients/caregivers. In addition, the PAQLQ and PACQLQ were replicable in participants who remained stable [90].

Asthma Therapy Assessment Questionnaire

Skinner and his colleagues developed the Asthma Therapy Assessment Questionnaire (ATAQ) for children and adolescents to assess the risk of adverse outcomes of asthma [138]. ATAQ is a *"brief, parent-completed questionnaire that generates indicators of potential care problems in several categories, including symptom control, behavior and attitude barriers, self-efficacy barriers, and communication gaps."* They validated the questionnaire among parents of 434 children aged 5-17 years being treated for asthma.

Pulmonary function

I assessed pulmonary function by recording three values, Forced Vital Capacity (FVC), Forced expiratory volume in 1 sec (FEV1), and forced expiratory flow 25-75% (FEF25-75%). FVC is *"the total volume of air expired after a full inspiration. Patients with obstructive lung disease (e.g., asthma) usually have a normal or only slightly decreased vital capacity. Patients with restrictive lung disease have a decreased vital capacity"*. FEV1 is *"the volume of air expired in the first second during maximal expiratory effort. The FEV1 is reduced in both obstructive and restrictive lung disease. The FEV1 is reduced in obstructive lung disease because of increased airway resistance."* FEF25-75% is *"the average rate of airflow during the importation of the forced vital capacity. This is reduced in both obstructive and restrictive disorders."* [1]

I used FEF 25-75% since it is a sensitive index of airway obstruction. FEF 25-75% was correlated with bronchodilator responsiveness in asthmatic children with normal FEV1 [98, 136].

6.1.2 Participants

I conducted this study at the private practice. Eleven physicians at the practice were recruited. In order to participate in our study, pediatric asthma patients had to be ten

[1] http://meded.ucsd.edu/isp/1998/asthma/html/spirexp.html

years of age or older, have their own mobile phone, and be able to read at a 5th grade level. In addition, children had to be regular patients who had met the healthcare providers at least once before they participated in the study. After patients decided to participate in the study, I recruited their caregivers. I randomly assigned the 30 children to one of the three groups: 1) the Control group, which received no messages from the SMS service; 2) the Query group, where they were to respond to questions about their asthma symptoms raising percieved severity of asthma in "Individual belief" (using the query version of our system); or 3) the Query&Knowledge group, where they were queried about their asthma symptoms raising percieved severity of asthma in "individual beliefs", and given information to improve their asthma knowledge in "modifying factors" (using query and knowledge version of our system). Patients who agreed to be in this study received $25 at the end of the first doctor's visit and after completing a series of pre-study materials, and another $25 after a final exit interview after their second doctor's visit. After assigning participants to groups, we excluded 3 physicians who did not have any patients in the study.

6.1.3 Procedure

The duration of the study is the time between two scheduled visits to the doctor's office, typically 3-4 months. Patients that are assigned to the intervention groups received SMS messages every day (Query&Knowledge group) or every other day (Query group). Physician participants could access the Physician's dashboard to review the status of their patients and receive alerts via email when a patient responses to $2 \sim 3$ weight questions. I will describe our study method in three phases (see Table 6).

Table 6: Research tools used in each phase.

	1st doctor's visit	Between visits	Follow up visit
Patient	•Asthma knowledge test •Pre-survey •PAQLQ •Pulmonary function data	•SMS log	•Asthma knowledge test •Post-survey •PAQLQ •Pulmonary function data •Interview
Caregiver	•Pre-survey •PACQLQ		•Post-survey •PACQLQ •Interview
Physician	•Pre-survey	•Dashboard log	(Post-survey in the second deployment)

First doctor's visit

At the time of the first doctor's visit, caregivers were given a consent form for themselves, and another to provide consent for their child to be in the study. For their portion of the study, they were asked to fill out a set of surveys about their technology usage and the Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ) to assess the issues that the parents of pediatric asthma patients have. Once the child agreed to participate in the study, I collected basic demographic information. The child also completed surveys about technology usage, asthma knowledge, and the Pediatric Asthma Quality of Life Questionnaire (PAQLQ), to assess the functional problems (physical, emotional and social). The clinical research staff conducted a pulmonary function test data to record FEF 25-75%. Patients were told that their physicians would be able to view the responses they sent via SMS.

Participating physicians were scheduled for an introductory survey (see Appendix D). During this time, I gave them a brief tutorial on how to use the Physician's Dashboard to monitor their patients' SMS responses. Physicians were made aware that they might not have access to the Physician's dashboard if they did not have patients

selected to participate in the study or only had patients that were randomly assigned to the control condition.

During the study

My system logs SMS data transactions and the usage of the Physician's Dashboard.

Follow up visit

During the next follow up visits, I administrated a number of surveys including the asthma knowledge test, PAQLQ, ATAQ, and pulmonary function test with pediatric asthma patients. Parents were given surveys that included the PACQLQ. I conducted interviews with participants to understand how they used the SMS service. These interviews were recorded and transcribed for further analysis.

6.1.4 Results

This section consists of four parts: 1) characteristics of communication technology usage in pediatric asthma patients and their caregivers; 2) intervention results; 3) continuous assessment of ATAQ scores; and 4) usage of communication technologies. In all cases where we compare differences between groups, I will present both the p value and the effect size. The effect sizes, r, calculated based on Cohen's formula, were interpreted according to Cohen's guidelines of <0.1 for a small effect size, 0.5 for a medium effect size, and >0.8 for a large effect size (In ANOVA, $\eta^2 = 0.01$ (small), 0.059(medium), 0.138(large)) [30, 47]. Thus, if I have medium or large effect size, the statistical outcomes are still valuable.

Figure 18 shows the flow chart of pediatric asthma patients through the trial, and Table 7 shows the basic information of pediatric asthma patients in the study.

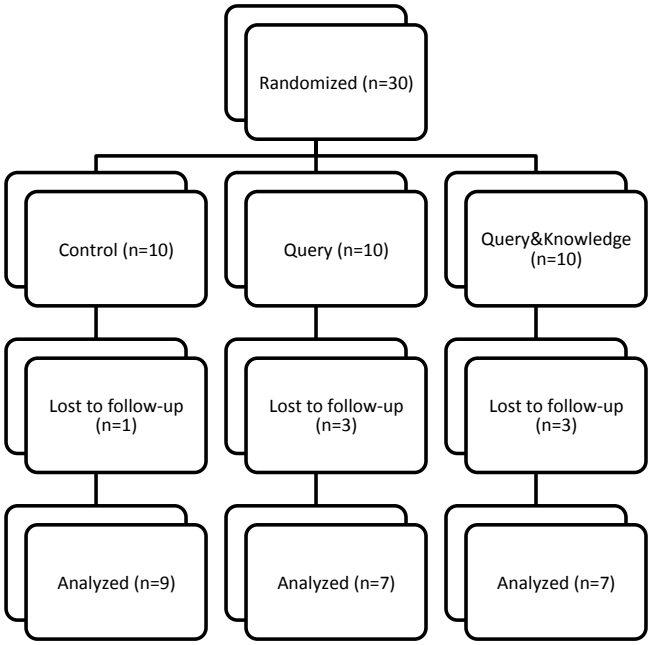


Figure 18: The flow chart of the trial.

Table 7: Enrollment table of the pediatric participants through the study and the age, sex, insurance types of participants at the follow up visits.

	Control	**Query**	**Query & Knowledge**
Sex (Female/Male)	4/5	3/4	2/5
Age	14.5±2.2 (median 14)	13.6±1.9 (median 13)	12.3±2.4 (median 12)

Insurance Type (Number of Participant)	**Control**	**Query**	**Query & Knowledge**
Private	8	5	5
Medicaid	1	1	2
Self paid	0	1	0

6.1.4.1 Characteristics of Participant and ICT usage

All 23 families reported that they had Internet access at home. Pediatric participants were using the Internet about the same amount of time (1.5 hours per day) as their caregivers (2 hours per day). Only 4 pediatric participants and 6 caregivers had used the Internet as a tool for asthma management, and only one family reported that they had used SMS for asthma management before the study. However, they had never used these media regularly for asthma management.

For mobile service usage, all families had a text plan. While 17 caregivers had a data plan, only 11 children had a data plan. Thirteen pediatric participants sent over 300 text messages a month.

6.1.4.2 Health Outcomes

Baseline at the first doctor's visit My pre-study survey indicates that the control and two intervention groups did not differ on any meaningful clinical or psychosocial characteristics (see Table 8). I did not find significant age, asthma knowledge, quality of life perception (PAQLQ, PACQLQ), or pulmonary function (FEF 25-75%) differences across all groups. In terms of the scores of asthma knowledge test, I found that age was significantly correlated with the scores ($r = 0.62$, $p = .0018$). Caregiver's quality of life score (PACQLQ) was significantly correlated with their child's quality of life score (PAQLQ) ($r = 0.624$, $p = .0015$).

Final outcomes I had complete data for twenty-three pediatric asthma patients and six physicians. Seven patients did not have a follow up visit after their initial visits. The children who did not have follow-up visits in the intervention groups had no difference between the "rolling ATAQ" scores, which is the sum of the points for a given response set, and the response rates to the SMS queries compared to children that completed the study. Since it was our goal to use an ecologically valid process,

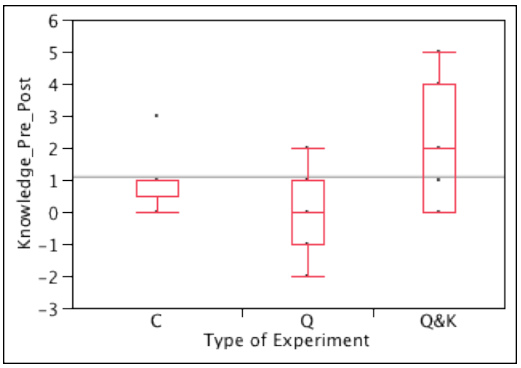
I did not encourage participants to attend a follow up visit.

The time between two visits for the 23 completed participants ranged from 92 to 395 days (median 114, mean 162 days). This is the expected lapse between office visits for children with moderate to severe asthma.

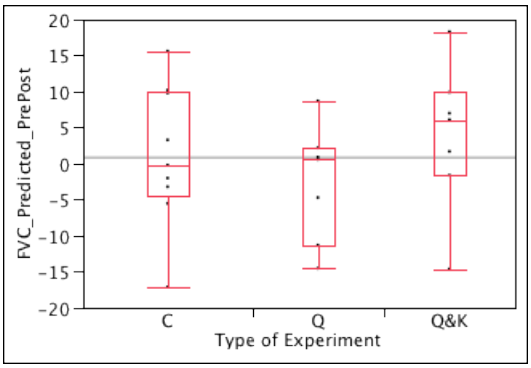
To test hypothesis *H1: Pediatric asthma patients answering regularly-administered questions about their asthma symptom/management via SMS will demonstrate better health outcomes than a control group of asthma patients, as measured both by a quality of life questionnaire and a pulmonary function test*, I compared the pre-post differences of PAQLQ and FEF25-75% between the control and the Query group (see Table 8). I found that patients answering regularly-administered questions about their asthma symptom/management did not demonstrate better health outcomes, as measured both by quality of life questionnaire and pulmonary function test, as compared to control. Hence, I reject hypothesis H1.

Table 8: Clinical and psychosocial outcomes (shading cells: statistically significant difference).

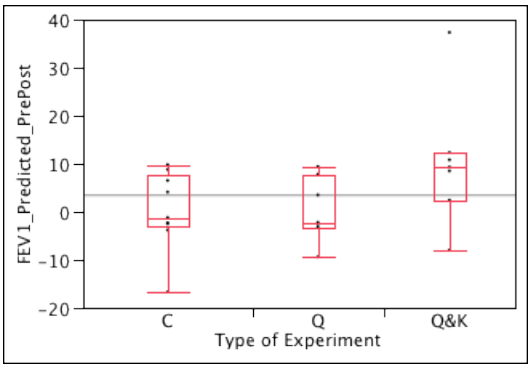
	Control (n = 9)		Query (n = 7)		Query & Knowledge (n = 7)	
Measures	***Pre***	***Post***	***Pre***	***Post***	***Pre***	***Post***
Knowledge	13.6±1.2	14.6±1.5	13.6±1	13.6±1.5	12.7±2.0	15±1.2
PAQLQ (Total)	5.8±0.8	6.2±0.7	5.7±1.2	6.1±1.0	4.6±1.5	4.8±2.0
PAQLQ (Activity Limitation)	4.7±1.5	5.6±1.4	4.9±2.0	5.2±1.4	4.2±1.0	4.1±1.8
PAQLQ (Symptoms)	5.8±1.1	6.1±0.9	5.8±1.3	6.3±0.7	4.3±1.7	4.9±1.9
PAQLQ (Emotional Function)	6.6±0.4	6.7±0.3	5.9±1.2	6.3±1.0	4.8±1.7	5.0±2.4
PACQLQ (Total)	6.0±1.2	6.4±1.0	5.8±2.0	6.1±1.2	5.2±1.2	5.9±1.3
PACQLQ (Activity Limitation)	5.8±1.4	6.4±1.2	5.5±2.3	6.0±1.5	5.0±1.6	5.9±1.8
PACQLQ (Emotional Function)	6.1±1.2	6.4±0.8	5.9±1.8	6.1±1.3	5.2±1.0	5.9±1.2
FVC%	101.9±10.0	103.2±8.7	91.0±9.4	88.4±9.7	99.4±4.7	103.2±11
FEV1%	96.6±11.9	96.9±10.6	86.1±12.0	86.6±7.4	89.4±19.2	99.7±10.8
FEF25-75	85.2±24.1	85.1±22.3	77.9±25.1	79.1±20.0	74.3±31.4	96.0±32.6



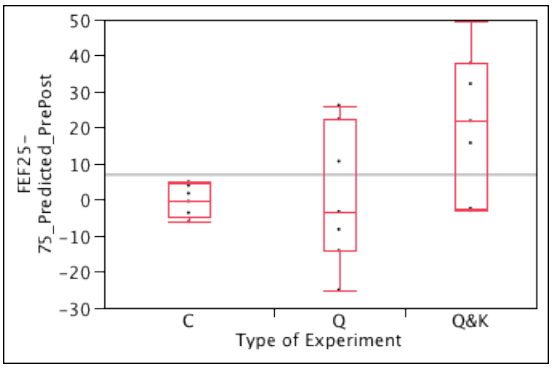
(a) Diffrence of pre-post knowlege score



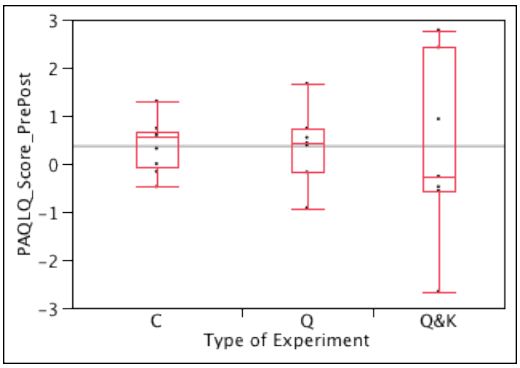
(b) Diffrence of pre-post FVC%



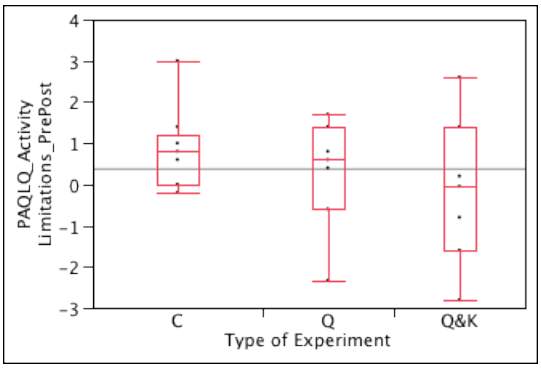
(c) Diffrence of pre-post FEV1%



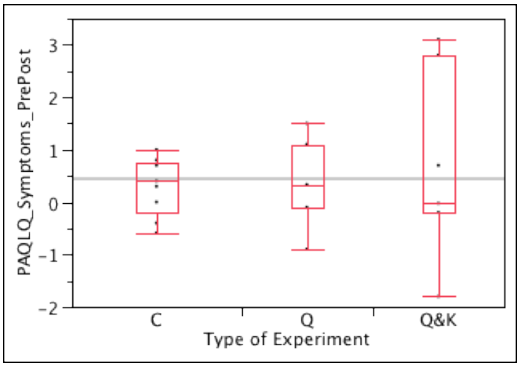
(d) Diffrence of pre-post FEF25-75%



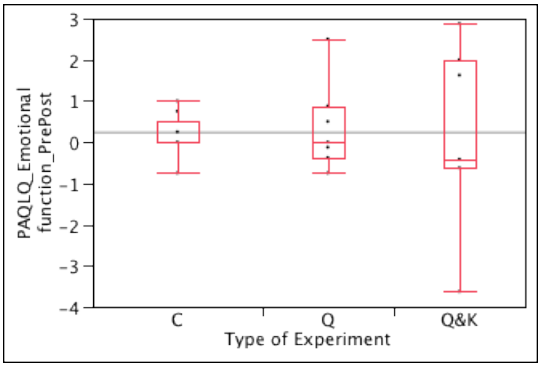
(e) Diffrence of pre-post PAQLQ



(f) Diffrence of pre-post PAQLQ(Activity)



(g) Diffrence of pre-post PAQLQ(Symptom)



(h) Diffrence of pre-post PAQLQ(Emotion)

Figure 19: Box plots and historgram of health outcomes.

To test hypothesis *H2: Pediatric asthma patients answering regularly-administered questions about their asthma symptom/management via SMS and receiving regularly-administered information via SMS intended to increase their knowledge about asthma will demonstrate better health outcomes, as measured both by a quality of life questionnaire and a pulmonary function test, compared to those receiving only regularly-administered SMS questions and controls*, I compared the pre-post differences of PAQLQ and FEF25-75% between the Query group and the Query&Knowledge group, and the Control group and Query&Knowledge group (see Figure 19). PAQLQ improvement in the Query&Knowledge group was not statistically different from the query group or the control group when I compared means. However, Juniper suggests using the difference in score that can be considered clinically meaningful [81]. This is the Minimal Important Difference (MID) defined as *"the smallest difference or change in score which patients perceive as beneficial and would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's management."* This MID in PAQLQ and PACQLQ is 0.5 on the 7-point scale based on Juniper's suggestion. The difference between pre- and post- PAQLQ (symptom) in the Query&Knowledge was 0.625, which is bigger than MID. Thus, there was meaningful improvement of PAQLQ in symptoms (see Table 9).

Table 9: The Minimal Important Difference between pre and post scores in PAQLQ and PACQLQ (shading cells have the MID (>0.5)).

Measures	Control (n = 9)	Query (n = 7)	Query & Knowledge (n = 7)
PAQLQ (Total)	0.39±0.53	0.38±1.37	0.31±1.89
PAQLQ (Activity Limitation)	0.84±0.97	0.28±1.37	-0.15±1.81
PAQLQ (Symptoms)	0.32±0.55	0.41±0.85	0.625±1.76
PAQLQ (Emotional Function)	0.17±0.50	0.38±1.08	0.17±2.19
PACQLQ (Total)	0.37±0.81	0.27±1.62	0.74±1.36
PACQLQ (Activity Limitation)	0.56±0.70	0.54±2.95	0.86±1.81
PACQLQ (Emotional Function)	0.29±0.93	0.16±1.04	0.68±1.21

I found statistically significant differences for the FEF25-75% in the Query&Knowledge group compared to the Control group and Query group ($F(2,20) = 4.6619$, $p = .0218$, effect-size $\eta^2 = 0.32$). Patients in the Query&Knowledge group also had significant improvement of asthma knowledge compared to the other two groups ($F(2,20) = 4.2363$ $p = 0.0292$ effect size $\eta^2 = 0.3$). Thus, pediatric patients answering regularly-administered questions about both asthma management and information via SMS demonstrated better pulmonary function, symptom improvement in PAQLQ, and increased their knowledge about asthma compared to those receiving only regularly-administered SMS questions or no SMS questions.

6.1.4.3 Continuous assessment of ATAQ scores

To test hypothesis *H3: The "rolling ATAQ" score calculated by the answers of the SMS queries will provide continuous assessments of pediatric asthma management when compared to the standard ATAQ score*, I calculated the correlation between the last "rolling ATAQ" scores in the SMS service and the ATAQ score at the follow up visit. The rolling ATAQ scores of the participants, which my system calculated based

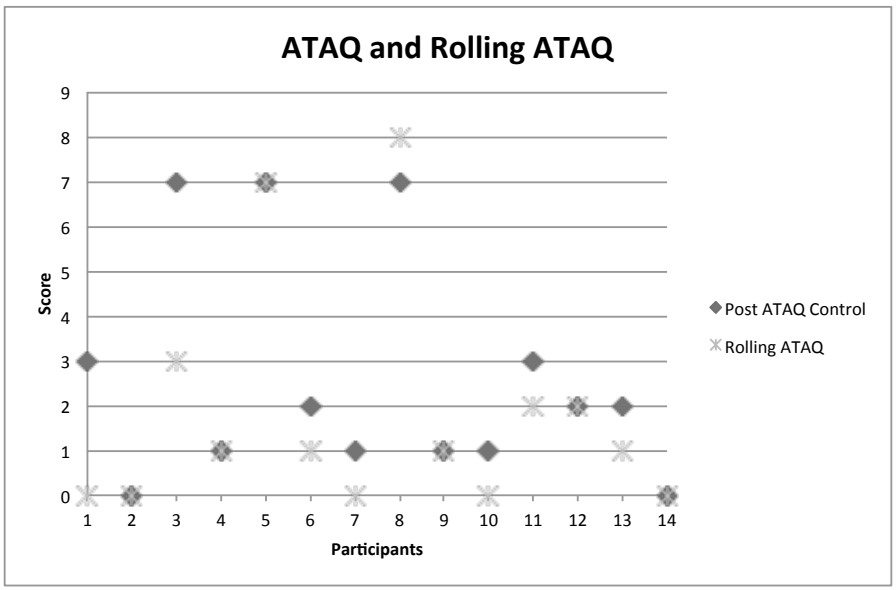


Figure 20: The (original) ATAQ score and the last "rolling ATAQ" score at the follow up visits.

on their recent 15 answers at the follow up visits, were significantly correlated with total scores in the traditional ATAQ at the follow up visits ($r = 0.868$, $p < .0001$) (see Figure 20). This shows concurrent validity, in which "rolling ATAQ" scores correlate well with the traditional ATAQ scores. Specifically, the "rolling ATAQ" score has a strong positive linear relationship ($r > 0.8$) with the standard ATAQ score when the two measures are taken at the same time [100]. However, the "rolling ATAQ" scores collected two months before the follow up visit were not correlated with the traditional ATAQ scores at the follow up visits. This means the "rolling ATAQ" score can have temporal granularity compared to the traditional ATAQ score. The PAQLQ scores, which we collected in the follow up visits, were significantly correlated with the rolling ATAQ scores at the follow up visits ($r = -0.89$, $p < .0001$).

Thus, the "rolling ATAQ" score calculated by the answers of the SMS queries provided approximate assessments of pediatric asthma management on a more frequent basis when compared to the standard ATAQ score.

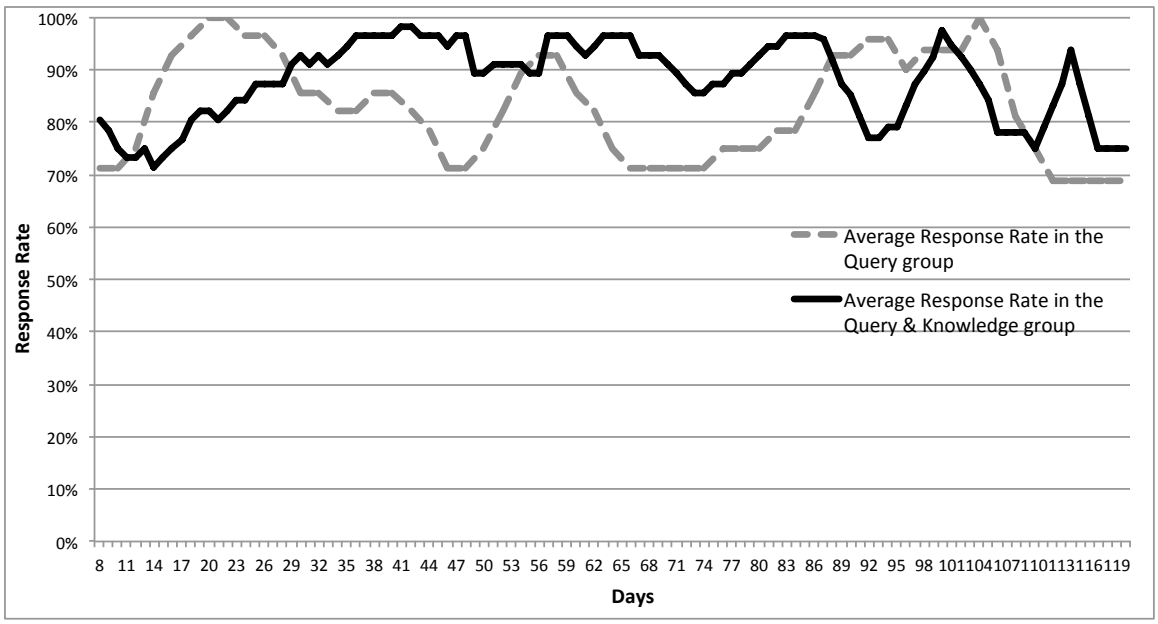


Figure 21: The overall response rate during the study.

6.1.4.4 Usage of communication technologies

Our SMS service sent a total of 1536 queries to 14 pediatric patients who were in the two experimental groups. The overall response rate was 83%, ranging from 75% to 99% (see Figure 21).

I found that SMSs usage did not decline during the study period. The average delay between questions and responses was 22 minutes. The Physician's dashboard system sent a total of 58 alerts to the physicians during the study. The physicians logged in the Physician's dashboard 36 times (62% - 36 out of 58). Table 10 shows the types each alert sent and the number of logins of the Physician's dashboard.

Table 10: The total number of alerts sent by patients via email to each physician and the number of logins by each physician.

Physician	Patients (Group)	Total Alert	Rescue Med.	Oral Steroid	ER visit	Hospitalization	New Set	# Of Clicks for Patient	# Of Logins
P1	B09 (Q)	6	4	0	0	0	2	11	**6**
P2	G11(QK)	0	0	0	0	0	0	7	**3**
P3	B05(Q)	1	0	0	0	0	1	0	**21**
	B10(Q)	9	4	0	0	0	5	0	
	B06(QK)	10	8	2	0	0	0	11	
	B11(QK)	9	4	1	2	0	2	2	
	P3 Total	*29*	*16*	*3*	*2*	*0*	*8*	*13*	
P4	B02(Q)	1	0	0	0	0	1	0	**0**
	B15(QK)	1	0	0	0	0	1	0	
	P4 Total	*2*	*0*	*0*	*0*	*0*	*2*	*0*	
P5	G02(Q)	1	1	0	0	0	0	13	**4**
	G03(Q)	3	1	0	0	0	2	2	
	P5 Total	*4*	*2*	*0*	*0*	*0*	*2*	*15*	
P6	B03(QK)	4	1	1	0	0	2	0	**0**
P7	B01(QK)	4	1	0	0	0	3	0	**0**
P8	G14(Q)	7	0	1	0	0	6	3	**3**
	G01(QK)	2	2	0	0	0	0	8	
	P8 Total	*9*	*2*	*1*	*0*	*0*	*6*	*11*	
Total		**58**	**26**	**5**	**2**	**0**	**25**	**96**	**37**

6.1.5 Discussion

I successfully deployed a new intervention for pediatric asthma management in an ecologically valid setting using a widely adopted mobile technology, SMS. The new intervention was found to have some positive effects on health outcomes and asthma knowledge of the patients. Patients readily adopted it and maintained a high rate of response throughout the intervention period. Thus, our system can provide the physicians constant assessment of their patients' asthma between visits. Some of the physicians responded positively to the use of the SMS and Physician's dashboard. In particular, physicians used the data from the Physician's Dashboard. They addressed the issues raised by patients' answers straight when the patients had a follow up visit.

In this section I will discuss the main findings and challenges for future designs that emerged from my analysis.

6.1.5.1 Health Improvement Outcomes

I received support for our hypotheses. Namely, I found that the pediatric asthma patients that both answered questions about their asthma symptom/management and received information about asthma showed improved health outcomes, as evidenced by quality of life and lung function analyses compared to the query only and control groups. This result is in line with the Health Belief Model (HBM), which indicates that both awareness and knowledge are crucial to individuals engaging in proactive behavior to improve their condition [130]. First, they felt that their knowledge was increased:

> *B3 QK-C "It (knowledge) helps me become more aware of what causes asthma."*

> *B6 QK-P "He seemed a lot more knowledgeable about asthma. He even talked to me some stuff."*

Two participants in the Query group and 3 participants in the Query & Knowledge group mentioned that receiving text messages reminded them to take medicine:

> *B3 QK-C "If I forgot my medicine in the morning, and I got the text, (I) remembered what I had to do (take medicine) after I got the text."*

> *B9 Q-C "It reminded me of taking the medications."*

I found differences in pulmonary function data, but not in all quality of life questionnaires (PAQLQ) except symptom measures, among the intervention groups. I can infer two reasons. First, the overall PAQLQ at the initial visit was so high that our intervention could not affect the change of the score significantly. The best score is 7, which means that the child has no perceived impairments due to asthma. The range of average PAQLQ score at the initial visit was from 4.6 to 5.8. Second, the

patients are heterogeneous in their responses to interventions [81]. Since my patients had different severities of asthma based on their lung function, it could have affected our results.

6.1.5.2 SMS as a Communication Tool in the Clinical Setting

One of the challenges in my study was to design and develop a sustainable technology that could be used in the context of a clinical setting. My SMS system was able to meet the challenge. My service had a response rate greater than 83%, sustained over duration of the study from 3 to 12 months. A previous study, which was conducted in 2004, with 12 participants reported a response rate of 69% for a two-month period [6]. Participants in my study (median age: 13 years old) were younger than those in the previous SMS study (38.5 years). The increased response rate in this study may be related to the fact that younger users lead the adoption and use of text messages [146]. Lastly, my system sent fewer text messages (at most one per day) than the previous study (four per day). As one participant described:

> *B6 QK-C "It was fun. I wanted to have more questions a day. I can answer two times a day because I like it."*

The other challenge for my system was to facilitate and improve current practices for pediatric asthma management. As I explained earlier, some pulmonologists utilize the standard ATAQ questionnaire (or similar instruments) during office visits. The standard ATAQ questionnaire asks for data over the previous four weeks leading up to the office visit. Since children visit the physician at most three or four times a year, physicians have sparse data with which to form an understanding of their patients' symptom history. My SMS study showed that patients are willing to provide continuous data about their symptoms. Further, my results show that the "rolling ATAQ" scores at the final visit were significantly correlated with the standard ATAQ scores that were administered during the office visit. However, this does not mean

the standard ATAQ score is equal to the "rolling ATAQ" score as you already saw the degree of correlation ($r = 0.868$). This suggests that SMS administration may be an appropriate way of administering the ATAQ questionnaire, although this is a claim that must be validated through further research.

The high rate of response during the four-month period of the study, the fact that most patients had text plans, and the similarities and differences between the "rolling ATAQ" and the standard ATAQ, together suggest that the use of SMS for question and answer exchanges may be a cost- and labor-effective way to keep physicians updated about their patients asthma status between scheduled visits.

6.1.5.3 Impact on Clinical Practice

Another goal of this study was to facilitate or improve the communication between patients and healthcare providers (specifically physicians). Although the size of my study limits the conclusions I can draw, I think it is worthwhile to mention some positive findings.

The log data shows that the physicians logged into the Physician's dashboard to review their patients' status (see Table 10 on page 98). Patient interview data indicated that this in turn affected conversations that took place during their medical check-ups. For example, one of the participants repeatedly answered that he was using oral steroids to manage his symptoms. This response led to the child being put into the Red Zone, which also resulted in the delivery of an email alert to the physician. When the patient visited the doctor's office, he explained how his doctor taught him what oral steroids are:

> *B6 QK-C "She did talk about a lot of text messages. I was confused [about] oral steroid [as compared] with ProAir [rescue bronchodilator medication]. She taught me the difference between the two."*

This last example points out that some of the terminology in the system might

limit its effectiveness. However, current terminology is often used in the doctor's office (and the physicians assumed that the children knew what this meant). Thus, presenting the various terms in the context of SMS queries could be an opportunity for physicians to confirm that their patients are aware of the distinctions between the different types of medicines. Another participant mentioned that her physician's access to her SMS responses led to a more focused conversation:

> *G3 Q-C "He already knew what I did, so he talked about what I was supposed to do."*

This shows that even though her doctor did not contact her between visits, he used data from the Physician's dashboard, which the SMS service provided, and that affected the conversation during the subsequent patient visit.

There was evidence that our SMS system indirectly mediated communication between patients and their parents. A number of patients and parents mentioned similar comments to those below. For example, one patient mentioned that she did not know what a term was in one of the text messages she received so she asked her mother about it.

> *B9 Q-C "I had to ask mom to tell me what it means . . . I didn't understand the question 'have you taken controller medication every day in the past 4 weeks?' "*

6.1.6 Implications for the Second Deployment

Participants in this study were largely from middle income families, as evidenced by the preponderance of private medical insurance. Since the socioeconomic status affect asthma mortality [55], and influences the prevalence and severity of asthma [48], I conducted a post-hoc analysis to understand how socioeconomic status (insurance type) predicted quality of life and physiological functions. I compared initial PAQLQ

scores and pulmonary functions between patients with private insurance and patients with public insurance. I found a disparity in quality of life ($t(21) = 2.0$, $p = .0298$, Cohen's d = 0.87, effect-size $r = 0.40$) and pulmonary functions between two groups (FEC%: $t(21) = 1.36$, $p = .095$, Cohen's d = 0.594, effect-size $r = 0.285$ / FEV1%: $t(21) = 1.38$, $p = .091$, Cohen's d = 0.602, effect-size $r = 0.288$). This result suggests that socioeconomic status can be an additional important independent factor influencing asthma management[47]. Thus, I decided to investigate how insurance type can affect health outcomes and the effectiveness of my intervention.

However, the first deployment had limitations. I did not have an experimental group that received only questions about general asthma knowledge. So I did not know the effect of the knowledge questions to compare effects between the two types of questions. Since using ICT in pediatric asthma management is in the early stages of development, it was difficult to design and assess the influence of specific constructs of the HBM embedded in the intervention on pediatric asthma management via text messages. To address the issue above, I had a knowledge-only question group instead of the Query group for the second deployment. Altering study design helped addressing socioeconomic status and knowledge as "Modifying factors" and perceived asthma severity as an "Individual belief" in design of the intervention for pediatric asthma management. Additionally, I did not gather and analyze physician participants' post-survey data since these physician participants were also in the second deployment study.

6.2 Second Deployment

The SMS service and Physician's Dashboard in the first deployment supported patients in the Query & Knowledge group to improve pulmonary function and quality of life. However, the limitation of my study design did not allow me to deepen understanding of how asthma symptom/management awareness and knowledge influenced

health outcomes. Though the clinical evaluation of the first deployment was informative as a proof-of-concept, I was interested in replicating the results of the first deployment, and how pediatric asthma patients and physicians use the system to answer the following questions:

RQ3. How do pediatric asthma patients and healthcare providers adopt a mobile and web service over the course of several months to improve asthma knowledge and awareness, and to affect the perceived quality of interaction with the healthcare providers, which can lead to improved quality of life and health outcomes?

RQ4. What is the impact of socioeconomic status, as an independent factor influencing quality of life, on the effectiveness of a mobile and web service? How does that impact differ for improvements in quality of life and health outcomes between patients with public insurance and patients with private insurance?

The major finding from the first deployment was that receiving/answering text messages could improve health outcomes. Additionally, the post-hoc analysis of the first deployment indicated that the type of health insurance could be a predictor to foresee the effectiveness of my intervention.

Two distinct purposes of the second deployment are: 1) to see if I can replicate the results of the first deployment with a large number of participants; and 2) to deepen our understanding of the role of additional modifying factors (socioeconomic status, knowledge) in the HBM constructs and the effect they have on.

6.2.1 Method

I modified my system and study design to address the additional issues identified in the first deployment. First, I implemented a knowledge-only version in the SMS service. Second, I recruited participants at the same location of the first deployment from two separate demographic groups (patients with private insurance and patients with public insurance). My modified system and study design addressed the following

research questions and hypotheses (below):

RQ3. How do pediatric asthma patients and healthcare providers adopt a mobile and web service over the course of several months to improve asthma knowledge and awareness, and to affect the perceived quality of interaction with the healthcare providers, which can lead to improved quality of life and health outcomes?

H3: The "rolling ATAQ" score calculated by the answers of the SMS queries will provide continuous assessments of pediatric asthma management when compared to the standard ATAQ score.

H4: Pediatric patients answering regularly-administered questions about their asthma symptom/management via SMS and receiving regularly-administered information via SMS that is intended to increase their knowledge about asthma will demonstrate better health outcomes, as measured both by a quality of life questionnaire and a pulmonary function test, as compared to those receiving only regularly-administered information and controls.

H5: Pediatric patients answering regularly-administered questions about their asthma symptom/management via SMS and receiving regularly-administered information via SMS will have better perceived quality of interaction with the healthcare providers, as measured by a Patient Reactions Assessment (PRA), as compared to those receiving only regularly-administered information and controls.

RQ4. What is the impact of socioeconomic status, as an independent factor influencing quality of life, on the effectiveness of a mobile and web service? How does that impact differ for improvements in quality of life and health outcomes between patients with public insurance and patients with private insurance?

H6: Pediatric asthma patients with public medical insurance answering regularly-administered questions about their asthma symptom/management via SMS and receiving regularly-administered information via SMS that were intended to increase their knowledge about asthma will demonstrate a larger effect size of health outcomes

than pediatric asthma patients with private medical insurance answering regularly-administered questions about their asthma management via SMS and receiving regularly-administered information via SMS, as measured both by a quality of life questionnaire and a pulmonary function test.

6.2.2 System Modification

The SMS service in the second deployment was the same as the first SMS service, except for the knowledge-only version instead of the query-only version. The SMS service sent questions about asthma symptoms/management and questions about asthma knowledge. In the knowledge-only version, one of fifteen true/false questions about general asthma knowledge (e.g., Asthma is a psychological condition. F=False T=True) was sent out every other day (see Appendix B). The system calculated rolling knowledge scores based on patients' most recent 15 answers. In order to increase the patient's knowledge about asthma, the SMS service sent out information about whether they answered the question correctly or not and then provided information related to the specific question. The patients' responses to the knowledge questions were aggregated in the Physician's Dashboard, and the system calculated the rolling knowledge scores whenever it had a new answer. The Physician's Dashboard in the second deployment had the same design as in the first deployment, since I did not want to the design change to affect the outcomes. This enabled me to compare the results between the first and the second deployment.

6.2.3 Study Design

In this section, I describe the details of the study. I recruited pulmonologists and pediatric asthma patients, and primary caregivers were recruited in the study during the period

6.2.3.1 Measures and Instruments

I used the same measures in the first deployment to test the previously stated hypotheses: asthma knowledge; quality of life; asthma therapy assessment questionnaire; and pulmonary function described in Chapter 5, section 6.1.1 on page 84. In addition to these measures, I added an instrument to measure the perceived quality of the patient–provider relationship, which is the Patient Reactions Assessment (PRA).

The Patient Reactions Assessment (PRA)

The PRA is a brief (15-item) measure, which is composed of three 5-item scales designed to measure the perceived quality of the patient–provider relationship [50]. The three measure groups include informative (Patient Information Index) and affective (Patient Affective Index) behaviors of the provider, and the patient's perceived ability to initiate communication (Patient Communication Index) about the illness.

The Patient Information Index represents the extent to which the patient perceives the healthcare providers as having provided information about the illness, and the extent to which the patient understands that information. The Patient Affective Index shows how much patients perceive the healthcare providers as valuing and respecting them. Both the Patient Information Index and the Patient Affective Index are related to what the patient perceives the provider contributes to the relationship. In contrast, the Patient Communication Index taps what the patient contributes to the relationship, in terms of perceived ability to initiate communication about the illness with a healthcare provider [50]. This measure was not designed specifically for children. However, this is the only validated survey for the relationship assessment.

6.2.3.2 Participants

The same site was used for the first and second deployment. I recruited eleven pulmonologists at the practice. In order to participate in my study, pediatric asthma patients had to be ten years of age or older, have their own mobile phone, be able to

read at a 5th grade level, and have either public or private medical insurance. Additionally, children had to be regular patients who had met the healthcare providers at least once before they participated in the study. After patients and their caregivers decided to participate in the study, I randomly assigned 30 patients with public insurance and 30 patients with private insurance to one of three conditions: 1) the Control group, which received no messages from the SMS service; 2) the Knowledge group, where they were asked to respond to questions about given information to improve their asthma knowledge (using the knowledge version of my system); or 3) the Query & Knowledge group, where they were queried about their asthma symptom/management and given information to improve their asthma knowledge (using the query and knowledge version of our system). Patients who agreed to be in this study received $25 at the end of the first doctor's visit and after completing a series of pre-study materials and another $25 after a final exit interview, which occurred after their second doctor's visit.

6.2.3.3 Procedure

The duration of the study was the time between two scheduled visits to the doctor's office. Patients that are assigned to the intervention groups received SMS every day (Query & Knowledge group) or every other day (Knowledge group). Physician participants had access to the dashboard to review the status of their patients and receive alerts via email when a patient was in the red zone. I will describe the second deployment study method in three phases (see Table 11).

Table 11: Research tools used in each phase.

	1st doctor's visit	**Between visits**	**Follow up visit**
Patient	• Pre-survey • Asthma knowledge test • ATAQ • PAQLQ • **Patient Reactions Assessment (PRA) (New)** • Pulmonary function data	• SMS log	• Post-survey • Asthma knowledge test • ATAQ • PAQLQ • **PRA (New)** • Pulmonary function data • Interview
Caregiver	• Pre-survey • PACQLQ		• Post-survey • PACQLQ • Interview
Physician	• Pre-survey (if pulmonologists were not in first deployment)	• Dashboard log	• Post-survey

First doctor's visit This was proceeded as in the first deployment. I gave each caregiver a consent form for him or herself, and another to provide consent for his or her child to be in the study. For the caregivers' portion of the study, I asked them to fill out a set of surveys about their technology usage and the PACQLQ. Once the child agreed to participate in the study, I collected basic demographic information. The child completed surveys about technology usage, asthma knowledge, ATAQ, PAQLQ while they he/she was waiting for a doctor. The child completed Patient Reactions Assessment (PRA) after meeting with the doctor. The clinical staff conducted pulmonary function tests. I told patients that their main physicians would be able to view the responses they sent via SMS.

Each of the participating physicians was scheduled for an introductory survey when they began the second deployment. During this time, I gave them a brief tutorial on how to use the Physician's Dashboard to monitor their patients' SMS data if possible. Physicians were made aware that they might not have access to the Physician's Dashboard if they did not have patients selected to participate in

Table 12: Enrollment table of the pediatric participants, their ages and genders, through the study and at the follow up visits.

Variable	Patients with public insurance			Patients with private insurance		
	Control	***Knowledge***	***Query& Knowledge***	***Control***	***Knowledge***	***Query& Knowledge***
Female	2	3	4	4	5	3
Male	4	4	4	2	3	4
Age	11.5±0.8	13.0±0.7	14.7±0.7	12.3±0.7	14.0±0.7	12.0±0.7

the study, or if they only had patients that were randomly assigned to the control condition.

During the study

My system logged SMS data transactions and the usage of the Physician's Dashboard.

Follow up visit

I administrated a number of surveys including the asthma knowledge test, ATAQ, PAQLQ while they were waiting for a doctor. The clinical staff conducted pulmonary function test before the child met with the doctor. The child filled out PRA after meeting with the doctor. After meeting with their doctors, I conducted interviews with the participants, who were in the intervention groups, to understand how they used the SMS service. I recorded and transcribed these interviews for further analysis. I will show the analysis of interview data in section 6.3.

6.2.4 Results

This section consists of four parts: 1) characteristics of communication technology usage in pediatric asthma patients and their caregivers; 2) intervention results; 3) continuous assessment of ATAQ scores; and 4) usage of communication technologies.

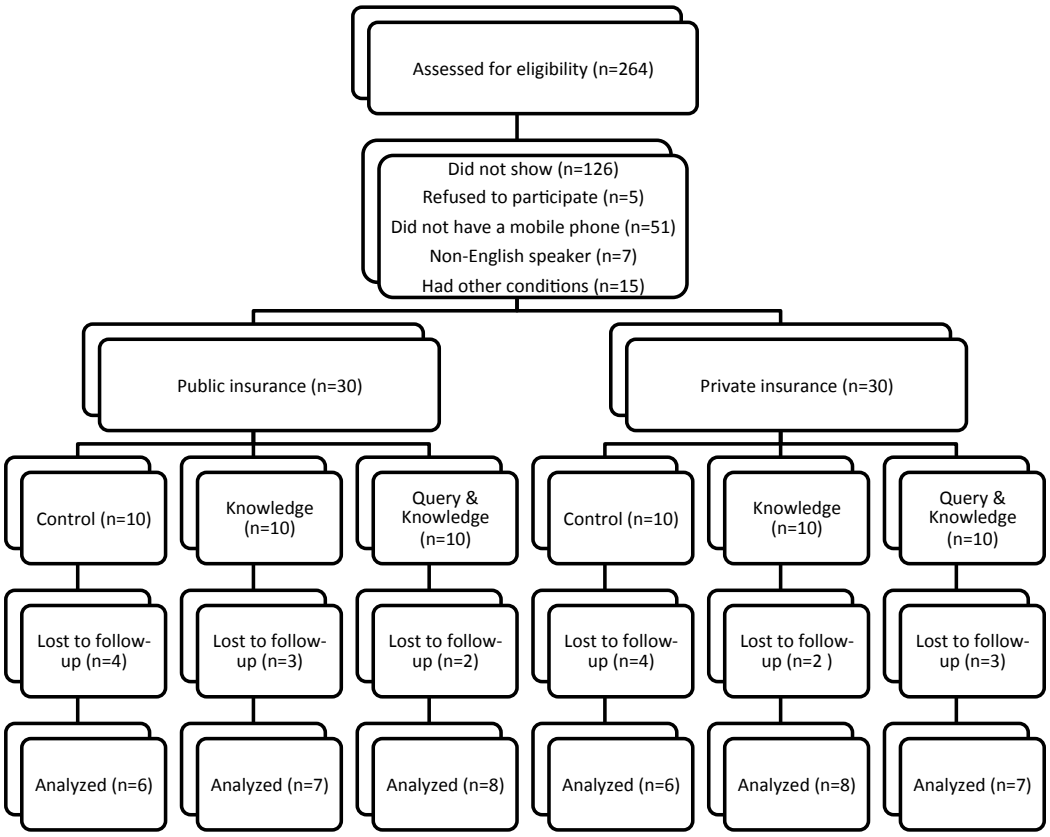


Figure 22: Progress of participants through the trial.

Progress of participants through the trial is shown in Figure 22. Table 12 shows the basic information of pediatric asthma patients in the study.

6.2.4.1 Characteristics of Participant and ICT usage

Pediatric asthma patient and caregiver Forty families reported that they had Internet access at home. Pediatric participants were using the Internet for less time (1.9 hours per day) than their caregivers (2.9 hours per day). Only 5 pediatric participants and 14 caregivers had used the Internet as a tool for asthma management, and 2 pediatric patients and 4 caregivers reported that they had used SMS for asthma management before the study. However, they had never used these media regularly for asthma management.

For mobile service usage, forty children had a text plan. While 32 caregivers had a data plan, 24 children had a data plan. Thirty-eight children sent text messages daily,

Table 13: Characteristics of participants and ICT usage.

	Public insurance (n = 21)	**Private insurance (n = 21)**
Internet usage time (child)	2.18 hours	1.7 hours
Internet usage time (parent)	3.17 hours	2.58 hours
Internet for asthma management (# of child / # of parent)	2/5	3/9
Text plan (# of child / # of parent)	20/20	20/21
Data plan (# of child / # of parent)	11/15	13/17
SMS for asthma management (# of child / # of parent)	2/2	0/2
Daily text user (child)	20	18
Over 300 text messages a month	9	6

and 15 pediatric participants sent over 300 text messages a month (see Table 13).

Pulmonologist Only two pulmonologists were using the Asthma Control Test [112] to assess asthma control while 8 pulmonologists were not using any questionnaires during the visits. For technology usage, all pulmonologists were using EMR almost every hour. Other results are shown in Appendix G.

6.2.4.2 Health Outcomes

Baseline at the first doctor's visit - Public insurance My results indicated that the three intervention groups from participants with public insurance did not differ on any meaningful clinical or psychosocial characteristics except age. The mean age in the control group is younger than other two groups'. There are interesting correlations in the baseline. First, ATAQ scores were correlated with PAQLQ and PACQLQ (r = -0.721, p <.0001; r = -0.697, p <.0001). This showed that my measures

in the initial visits had concurrent validity, which demonstrates where the validated measures are well correlated[100]. Second, ages were significantly correlated with their asthma knowledge scores ($r = 0.450$, $p = .00408$). This result is in line with other's findings [107].

Baseline at the first doctor's visit - Private insurance No difference in meaningful clinical or psychosocial characteristics was identified between groups at the baseline. I did not find significant age, asthma knowledge, quality of life or pulmonary function (FEF 25-75%) differences across all participants. There are interesting correlations in the baseline. As we saw with the correlations in the pool of patients with public insurance, ATAQ scores were correlated with PAQLQ and PACQLQ (r = -0.84, $p <.0001$; r = -0.53, $p = 0.014$). However, ages was not correlated with their asthma knowledge scores. Patients with private insurance might have better asthma education that patients with public insurance did since income disparity could impact asthma education [3]. The knowledge scores in patients with private insurance were higher than the patients with public insurance.

Final outcomes - Public insurance I have complete data for 21 pediatric asthma patients with public insurance. Nine patients did not have a follow up visit after their initial visit.

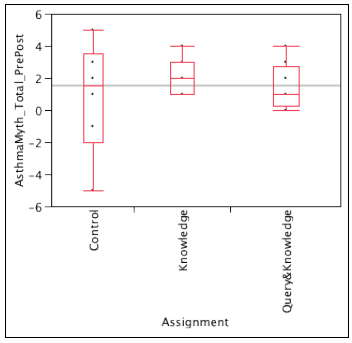
Since the goal was to use an ecologically valid process, I did not encourage participants to attend a follow up visit. The time between the two visits for the 21 completed participants with public insurance ranged from 58 to 152 days (median 102, mean 99 days). This is the expected lapse between office visits.

To test hypothesis *H4*, I compared the pre-post differences of PAQLQ and FEF25-75% between the control and the two intervention groups (see Table 14 and Figure 23). Since I had age difference, I used ANCOVA to conduct effect test. I could not find that age difference had an effect on the outcome ($p = 0.2799$); however, group had an

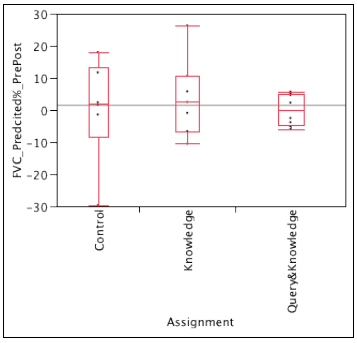
Table 14: Clinical and psychosocial outcomes – public insurance (shading cells: statistically significant difference).

	Control (n = 6)		**Knowledge (n = 7)**		**Query & Knowledge (n = 8)**	
Measures	***Pre***	***Post***	***Pre***	***Post***	***Pre***	***Post***
Knowledge	12.3±3.2	13.2±2.3	12.7±1.6	14.9±1.1	13.1±2.3	14.6±2.0
PAQLQ (Total)	4.3±1.2	4.4±1.2	4.8±1.5	4.9±1.8	5.7±1.5	5.9±1.3
PAQLQ (Activity Limitation)	3.6±1.6	3.2±1.3	4.5±1.8	4.4±1.7	5.3±1.4	5.6±1.8
PAQLQ (Symptoms)	4.2±1.5	4.3±1.2	4.9±1.2	4.8±1.8	5.9±1.5	6.0±1.4
PAQLQ (Emotional Function)	4.8±1.0	5.1±1.6	4.9±2.0	5.3±2.2	5.7±1.9	6.1±1.0
PACQLQ (Total)	3.9±1.2	3.8±1.4	4.9±0.7	5.4±1.0	5.8±0.7	5.8±0.7
PACQLQ (Activity Limitation)	3.6±1.1	4.0±1.6	4.9±1.2	5.3±1.2	6.2±0.6	6.0±0.8
PACQLQ (Emotional Function)	4.1±1.5	3.7±1.4	4.9±0.5	5.5±1.0	5.7±0.7	5.7±0.8
FVC%	97.3±11.5	97.7±16.3	96.5±13.6	100.4±4.4	91.3±7.8	91.4±11.3
FEV1%	93.4±12.1	88.9±20.2	79.6±17.4	89.9±16.4	87.4±16.7	87.2±16.1
FEF25-75%	91.1±26.6	73.5±27.5	51.3±21.0	65.5±25.7	78.2±32.0	84.2±31.7
PRA (II)	5.8±0.5	5.6±0.8	5.7±0.8	5.8±0.7	5.9±1.2	5.1±1.8
PRA (AI)	4.3±0.6	3.8±0.8	4.3±0.4	4.6±0.9.0	4.1±0.7	4.2±0.7
PRA (CI)	3.3±2.1	2.9±1.0	2.7±1.2	3.0±1.6	3.6±1.7	2.6±1.1

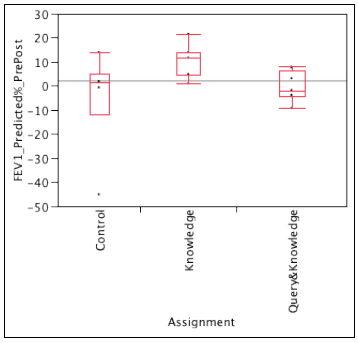
effect on the outcome ($p = 0.05$). I found that patients in the Query & Knowledge group demonstrated better health outcomes, as measured by a pulmonary function test, but not quality of life, as compared to the controls ($t(12) = 1.77$ $p = 0.05$, Cohen's $d = 1.02$, effect-size $r = 0.46$). However, there was no meaningful improvement of PAQLQ based on the Minimal Important Difference (MID). Thus, I partially accepted hypothesis H4. Additionally, I found that patients in the Knowledge group also demonstrated better pulmonary function outcomes, but not quality of life, as compared to controls ($t(11) = 2.22$ $p = 0.024$, Cohen's $d = 1.34$, effect-size $r = 0.56$).



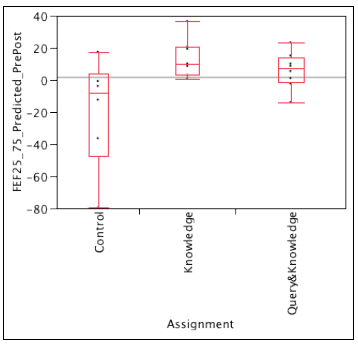
(a) Diffrence of pre-post knowledge score



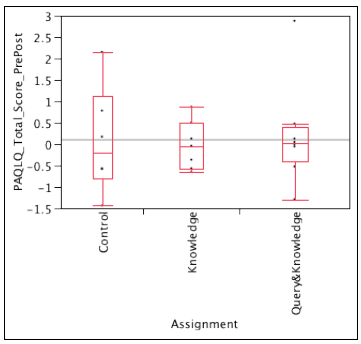
(b) Diffrence of pre-post FVC%



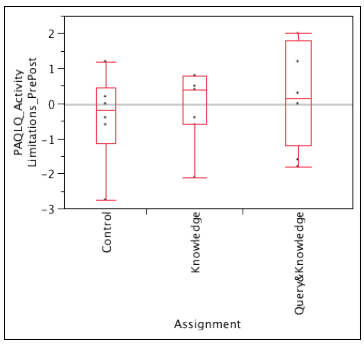
(c) Diffrence of pre-post FEV1%



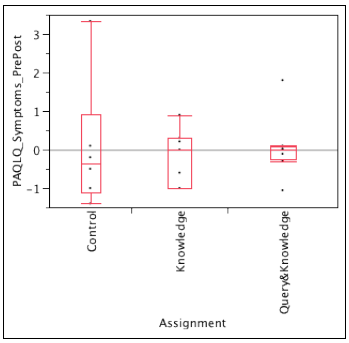
(d) Diffrence of pre-post FEF25-75%



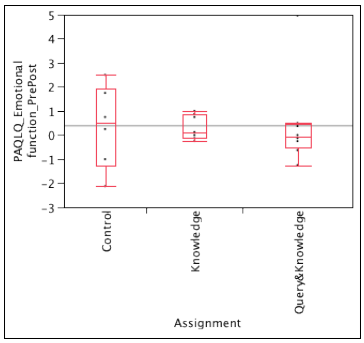
(e) Diffrence of pre-post PAQLQ



(f) Diffrence of pre-post PAQLQ(Activity)



(g) Diffrence of pre-post PAQLQ(Symptom)



(h) Diffrence of pre-post PAQLQ(Emotion)

Figure 23: Box plots and historgram of health outcomes – public insuarance.

Table 15: the Minimal Important Difference in PAQLQ and PACQLQ – public insurance (shading cells have the MID (>0.5).

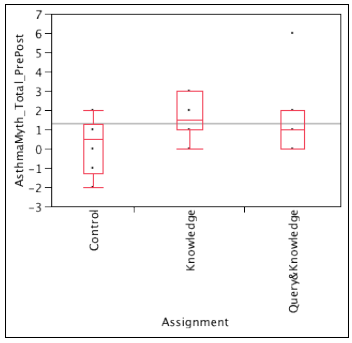
Measures	Control (n = 6)	Knowledge (n = 7)	Query & Knowledge (n = 8)
PAQLQ (Total)	0.09±0.43	-0.02±0.40	0.21±0.37
PAQLQ (Activity Limitation)	-0.40±0.53	-0.08±0.49	0.26±0.46
PAQLQ (Symptoms)	0.06±0.45	-0.17±0.42	0.06±0.39
PAQLQ (Emotional Function)	0.35±0.62	0.34±0.58	0.45±0.45
PACQLQ (Total)	0.15±0.33	0.50±0.30	-0.03±0.30
PACQLQ (Activity Limitation)	0.85±0.40	0.21±0.36	-0.17±0.36
PACQLQ (Emotional Function)	-0.16±0.38	0.63±0.34	0.04±0.34

To test hypothesis *H5*, I compared the pre-post differences of Patient Reactions Assessment (PRA) between the control and the other two groups (see Table 14). I found that both the Knowledge group ($t(11) = 1.93$ $p = 0.039$, Cohen's $d = 1.163$, effect-size $r = 0.503$) and the Query & Knowledge group ($t(11) = 1.71$ $p = 0.05$, Cohen's $d = 1.031$, effect-size $r = 0.458$) demonstrated better PRA improvements (Affective Index: how much patients perceive the healthcare providers as valuing and respecting them), as compared to the control. Hence, I accepted hypothesis H5.

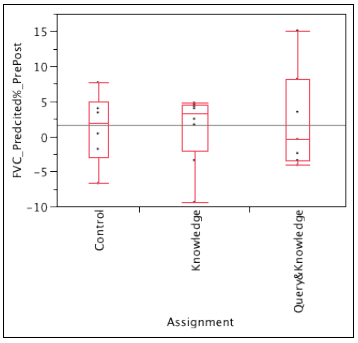
Final outcomes - Private insurance I have complete data for 21 pediatric asthma patients with private insurance. The time between two visits for the completed participants with private insurance ranged from 67 to 148 days (median 118, mean 115 days).

Table 16: Clinical and psychosocial outcomes – private insurance (shading cells: statistically significant difference).

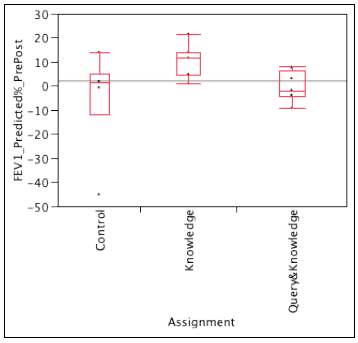
	Control (n = 6)		**Knowledge (n = 8)**		**Query & Knowledge (n = 7)**	
Measures	***Pre***	***Post***	***Pre***	***Post***	***Pre***	***Post***
Knowledge	14.0±0.9	14.2±1.0	13.4±1.2	15.1±1.4	13.9±2.4	15.6±0.8
PAQLQ (Total)	5.9±1.2	6.1±0.6	5.3±1.3	5.4±1.3	5.8±1.2	6.3±0.7
PAQLQ (Activity Limitation)	4.9±1.3	5.3±0.9	4.7±1.5	4.7±1.8	5.6±1.6	5.9±1.0
PAQLQ (Symptoms)	5.8±1.8	6.2±0.7	5.3±1.2	5.3±1.1	5.6±1.5	6.2±1.0
PAQLQ (Emotional Function)	6.6±0.5	6.5±0.5	5.8±1.5	5.8±1.6	6.2±1.0	6.8±0.3
PACQLQ (Total)	5.4±1.5	5.9±1.2	5.5±1.2	6.2±0.7	5.9±0.8	6.3±0.9
PACQLQ (Activity Limitation)	5.0±2.1	5.6±1.6	5.4±1.2	6±1.1	6.3±1.1	6.3±1.5
PACQLQ (Emotional Function)	5.6±1.2	6.1±1.0	5.6±1.2	6.2±0.5	5.7±0.8	6.3±0.7
FVC%	98.0±6.3	99.2±6.4	110.4±13.0	111.5±15.6	110.3±13.7	112.6±13.7
FEV1%	94.95±12.2	96.3±9.9	105.4±10.3	106.4±13.6	102.6±16.3	104.0±12.6
FEF25-75%	88.2±28.9	79.6±20.5	99.9±20.8	102.9±32.3	89.8±32.0	96.0±23.8
PRA (II)	5.5±1.0	5.3±0.9	5.4±1.2	5.9±0.7	5.2±1.2	5.3±1.1
PRA (AI)	4.5±0.7	4.2±0.8	4.3±0.4	4.6±1.0	4.1±0.5	4.2±0.7
PRA (CI)	2.7±1.8	2.9±0.8	3.0±1.2	3.3±2.1	2.3±0.8	3.3±2.1



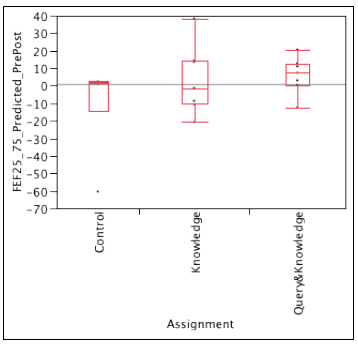
(a) Diffrence of pre-post knowledge score



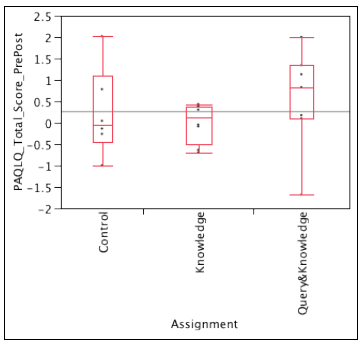
(b) Diffrence of pre-post FVC%



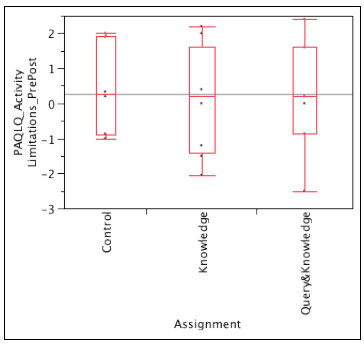
(c) Diffrence of pre-post FEV1%



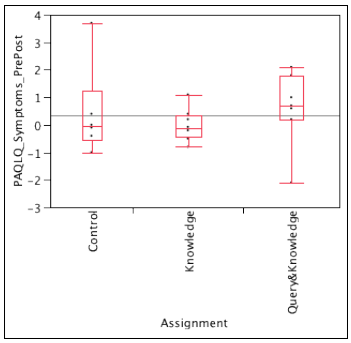
(d) Diffrence of pre-post FEF25-75%



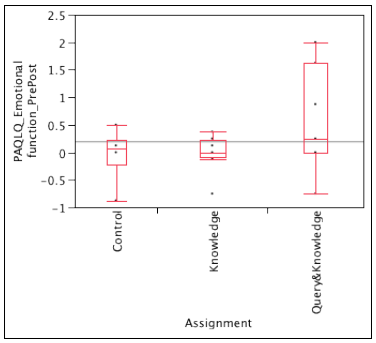
(e) Diffrence of pre-post PAQLQ



(f) Diffrence of pre-post PAQLQ(Activity)



(g) Diffrence of pre-post PAQLQ(Symptom)



(h) Diffrence of pre-post PAQLQ(Emotion)

Figure 24: Box plots and historgram of health outcomes – private insuarance.

To test hypothesis *H4*, I compared the pre-post differences of PAQLQ and FEF25-75% between the control and the other two groups (see Table 16 and Figure 24). I found that patients in the Query & Knowledge group demonstrated better health outcomes, as measured both by a quality of life questionnaire and a pulmonary function test, as compared to the controls ($t(11) = 1.41$, $p <.$ 0.09, Cohen's $d = 0.85$, effect-size $r = 0.391$[2]). There was meaningful improvement of PAQLQ based on the Minimal Important Difference (MID) (see Table 17). Thus, I accepted hypothesis H4. However, patients in the Knowledge group did not have better health outcomes.

Table 17: the Minimal Important Difference in PAQLQ and PACQLQ – public insurance (shading cells have the MID (>0.5).

Measures	Control (n = 6)	Knowledge (n = 8)	Query & Knowledge (n = 7)
PAQLQ (Total)	0.24±0.37	0.00±0.33	0.56±0.34
PAQLQ (Activity Limitation)	0.43±0.63	0.03±0.54	0.35±0.59
PAQLQ (Symptoms)	0.43±0.51	-0.01±0.44	0.61±0.46
PAQLQ (Emotional Function)	-0.02±0.26	-0.02±0.23	0.61±0.24
PACQLQ (Total)	0.47±0.35	0.62±0.30	0.42±0.32
PACQLQ (Activity Limitation)	0.54±0.55	0.60±0.48	-0.04±0.51
PACQLQ (Emotional Function)	0.44±0.30	0.60±0.28	0.60±0.28

To test hypothesis *H5*, I compared the pre-post differences of PRA between the control and the other two groups (see Table 16). I found that both intervention groups did not show better PRA improvements, as compared to control. Hence, I rejected hypothesis H5.

6.2.4.3 Continuous Assessment of ATAQ scores

To test hypothesis *H3*, I calculated the correlation between the "rolling ATAQ" scores in the SMS service and the traditional ATAQ score at the follow up visit. The "rolling

[2]level of significance is 10% (0.1)

ATAQ" scores at the follow up visits were significantly correlated with total scores in the traditional ATAQ at the follow up visits ($r = 0.862$, $p < 0.0001$) (see Figure 25). This shows concurrent validity, in which "rolling ATAQ" scores correlate well with the traditional ATAQ scores at follow up. Specifically, the "rolling ATAQ" score has a strong positive linear relationship with the standard ATAQ score when they represent an assessment over the same time period.

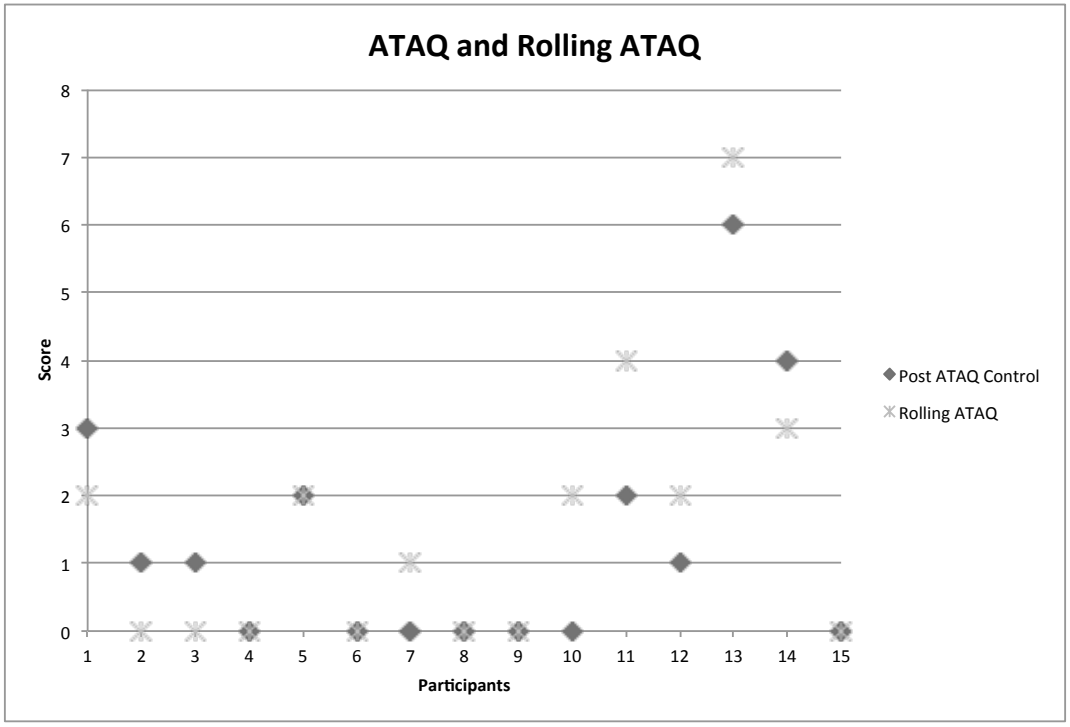


Figure 25: The (original) ATAQ score and the last "rolling ATAQ" score at the follow up visits.

The SMS service sent a total of 2095 queries to 30 pediatric patients who were in the two experimental groups (the Knowledge group: 15, the Query & Knowledge group: 15). The average response rate was 85.6% (Median 91.3%), ranging from 36% to 100% (see Figure 26). The Physician's Dashboard system sent a total of 20 alerts to the physicians during the study (see Table 18). There was no correlation between the number of alerts and the number of logins.

Table 18: The total number of alerts sent via email to each physician and the number of logins by each physician.

Physician	Patients(Gr	Total Alert	Rescue Mec	Oral Steroic	ER visit	Hospitalizat	New Set	# Of Logins
P3	PRG9(QK)	1	1	0	0	0	0	**0**
	PRG10(QK)	3	2	1	0	0	0	
	P3 Total	*4*	*3*	*1*	*0*	*0*	*0*	
P4	PUG14(QK)	6	5	0	0	0	1	**0**
	PRG12(QK)	0	0	0	0	0	0	
	PRB4(QK)	0	0	0	0	0	0	
	P4 Total	*6*	*5*	*0*	*0*	*0*	1	
P5	PUB2(QK)	0	0	0	0	0	0	**0**
	PUB6(QK)	1	1	0	0	0	0	
	P5 Total	*1*	*1*	*0*	*0*	*0*	*0*	
P6	PUG5(QK)	2	0	0	0	0	2	**1**
P7	PUB14(QK)	0	0	0	0	0	0	
P8	PUB9(QK)	3	2	0	0	0	1	
	PRB14(QK)	2	0	0	0	0	2	
	P8 Total	*5*	*2*	*0*	*0*	*0*	*3*	
P10	PRB11(QK)	1	0	1	0	0	0	**0**
P11	PUG1(QK)	1	1	0	0	0	0	**1**
Total		**20**	**12**	**2**	**0**	**0**	**6**	**2**

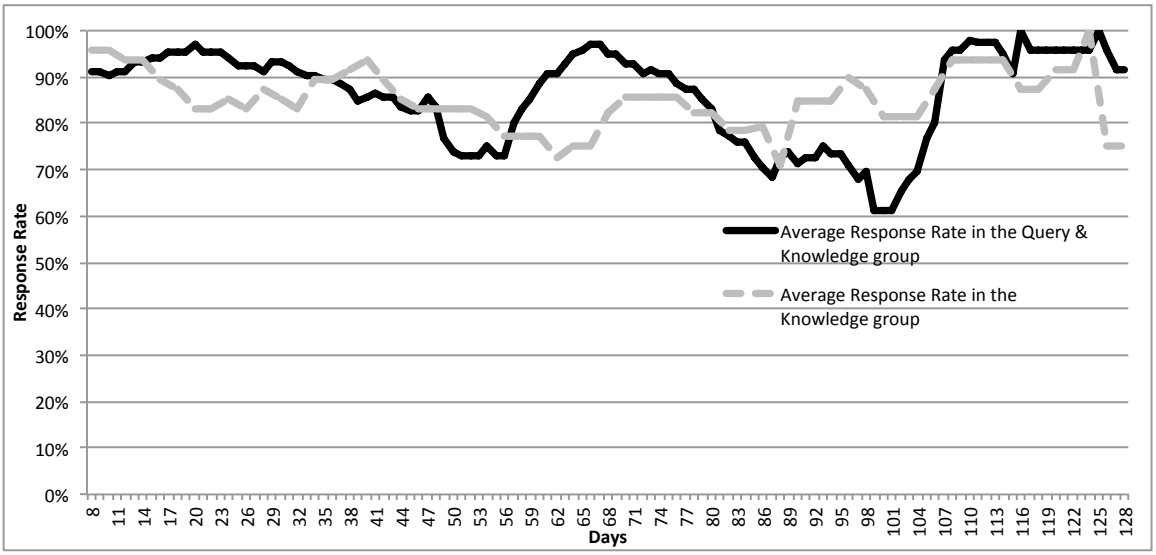


Figure 26: The overall response rate during the study.

6.2.4.4 The Effectiveness of the Intervention to Peadiatric Asthma Patients

To test *H6*, I compared the effect sizes between patients with the public and private insurance in the same intervention groups. To compare outcomes across studies, we use effect sizes [47]. As one can see Table 19, patients with public insurance in the intervention groups (medium effect size) had larger effect sizes as compared to patients with private insurance (small effect size). Effect size is *"simply a way of quantifying the size of the difference between two groups."*[3] Thus, patients with public insurance had larger improvement than patients with private insurance. Therefore, I accepted H6.

Table 19: The effect sizes between patients with public and private insurance in the intervention groups (FEF25-75%).

	Public	**Private**
	Effect size (compared to the Control group)	
Knowledge group	Cohen's $d = 1.34$ effect-size $r = 0.56$	Cohen's $d = 0.57$ effect-size r = 0.28
Query & Knowledge group	Cohen's $d = 1.02$ effect-size $r = 0.46$	Cohen's $d = 0.85$ effect-size $r = 0.39$

6.2.5 Post-hoc Analysis: Change in Knowledge and Perceived Severity

I investigated how knowledge and perceived severity changed after the intervention since I used the HBM to learn how constructs affected the health outcomes.

[3] http://www.leeds.ac.uk/educol/documents/00002182.htm

6.2.5.1 Public Insurance

I conducted paired t-test to see the improvement of knowledge. The Knowledge group and the Query & Knowledge group had statistically significant improvement ($t(6) = 5.3$ $p = 0.0009$, Cohen's $d = 4.374$, effect-size $r = 0.908$; $t(7) = 3$ $p = 0.01$, Cohen's $d = 2.268$, effect-size $r = 0.75$). For perceived severity of asthma, I asked children to assign their severity into one of four categories: 1)Intermittent – have symptoms 2 or less days per week; 2)mild – have symptoms more than 2 days per week; 3)moderate – have symptoms daily; and 4)severe – have symptoms throughout the day. To know how their perceived severity changed, I compared the correlations between their assignments and pulmonary functions at the initial and the follow up visits with Spearman's rank correlation (ρ). In the initial visits, I could not find any correlation in the three groups. In the follow-up visits, I found that the Query & Knowledge had statistically significant correlations between perceived severity with FEV1% and FEF25-75% ($\rho = -0.7910$ $p = 0.0194$; $\rho = -0.8456$ $p = 0.0082$). Thus, patients in the Query & Knowledge group perceived their symptom appropriately after answering the text messages about asthma symptom/management.

6.2.5.2 Private Insurance

The Knowledge group and the Query & Knowledge group had statistically significant improvement as I expected ($t(7) = 4.25$ $p = 0.0019$, Cohen's $d = 3.213$, effect-size $r = 0.849$; $t(6) = 2.2$ $p = 0.035$, Cohen's $d = 1.799$, effect-size $r = 0.669$). For perceived severity of asthma, I could not find any correlation in the three groups in the initial visits. In the follow-up visits. I found that the Query & Knowledge had a statistically significant correlation between perceived severity with and FEF25-75% ($\rho = -0.8214$ $p = 0.0234$). Thus, patients in the Query & Knowledge group perceived their symptom appropriately after answering the text messages about asthma symptom/management.

6.3 Interview with pediatric asthma patients, primary caregivers, and pulmonologists

In this section, I present the main themes that resulted from my interviews focusing on the usage of the SMS service, the change of asthma management, and the issues of intervention use. I interviewed parent–child pairs from 30 children and 28 primary care givers who had follow-up visits in order to have a better understanding of how they used SMS to manage asthma and the issues they had. I used the semi-structured interview as a methodology to understand the experiences of the participants with my interventions and the opportunities that they provided via these experiences. I also interviewed two pulmonologists to have a better understanding of how they used the Physician's Dashboard to manage their patients (see Appendix E for the interview questions).

6.3.1 Procedures

I conducted 20-minute semi-structured interviews with each parent child pair in a consulting room in the private practice at their follow-up visits. Parents and children were interviewed separately, though all parents stayed in the same room and were able to listen to the child's responses, which might have potentially affected the child's responses. Only one pediatric patient (17 years old) had the follow-up visit alone without his primary caregiver. The questions focused on the participants' general experiences with the interventions, how they managed asthma during the study, and how they talked to their healthcare provider during the follow-up visits. I asked a question about whether they were satisfied with the interactions through text messages. I found that some pediatric participants had trouble explaining what their experiences were. This limitation may not allow me to fully understand asthma management practices.

6.3.2 Analysis

I recorded and transcribed all interviews. One fellow researcher and I analyzed the interview transcripts by creating themes using thematic analysis [21]. The reason we used the thematic analysis was its flexibility. This method is originally independent of theory. However, this method can be used for both "essentialist and constructionist paradigms." An essentialist method reports experiences and meanings of participants while a constructionist method examines the ways in which events, meanings, and experiences are working in society [21].

Based on their guideline, we followed the four phases of analysis:

First, We generated inductive initial codes from the transcripts, which appeared intriguing to us. These codes identify a feature of our interview data. These codes, which is the most basic meaningful information, differ from the units of our themes.

Second, we searched for themes after finding and collating the codes. We refocused the codes at the broader level and collected relevant codes within the interesting themes. At this phase, we ended up with a collection of candidate themes.

Third, we reviewed and refined the themes we identified in the previous phase. We identified evident themes while merging/separating other themes. If we found a candidate theme problematic, we discarded the theme. At this phase, we had fairly good themes about our data.

Finally, we further refine our themes and then we collected interview data for each theme.

6.3.3 Result

I present my themes and the supporting evidence for each theme (see Figure 27). First, I discuss how asthma management changed. Second, I describe how the intervention affected knowledge. Third, I explain how the intervention influenced the

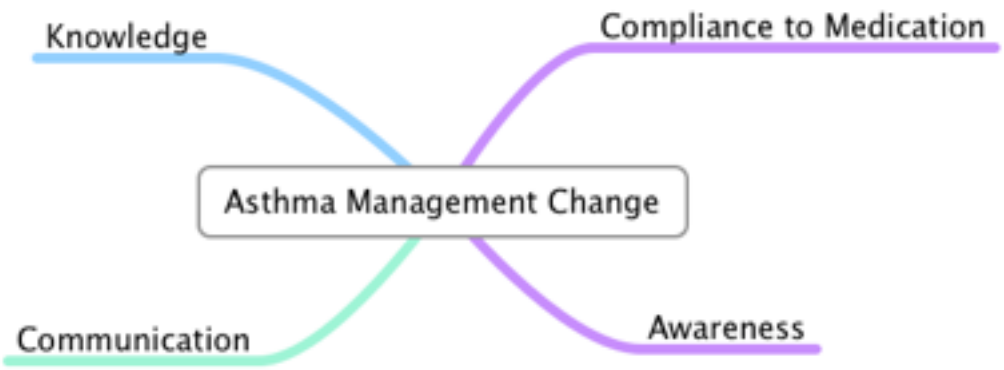


Figure 27: The emerging themes from interview data.

perceived asthma condition. Next, I show how the intervention facilitated communication. Finally, I discuss the experience of participants with the SMS service.

6.3.3.1 Theme 1: Change in medication compliance

Similar to the result of the first deployment study, the intervention changed asthma management. Specifically, children and parents mentioned that receiving the text messages worked as a reminder to take a medication. Receiving and answering the text messages was a cue to action to increase compliance to medication regimen. This was common in both the Knowledge group and the Query & Knowledge group. The text messages in the SMS service did not have any content which explicitly reminded them of taking a medication. Two pediatric asthma patients set the text receiving time when they wanted to take a medication:

> *PRB8 K-C*[4] *"I woke up .. whenever I saw it. Oh! I went to take my medicine."*

[4] *Interview quote starts with PR(Privte insuarance) or PU(Public insuarance), B(male participant) or G(female participant), then K(Knowledge group) or QK(Query & Knowledge group) - C(child) or P (parent)*

PUG15 K-C "I took my inhaler. When I got the text messages, I took the medicine."

PUB14 QK-C "Normally when I woke up, I took my inhaler two puffs every day, and after getting text messages, I did messages and then I took the medicine"

Primary caregivers (parents) mentioned that the children were more diligent to take a medication after receiving the text messages:

PUB15 K-P "It helped (name) out because it made him remember to take the medication"

However, many children and parents did not think they changed practices in pediatric asthma care. In other words, their change was sometimes not drastic but subtle. Some children did not notice the change of medication compliance:

PUB9 QK-C "I mean the same, I didn't really change anything, I just mostly answered the questions most time"

However, their caregivers perceived their subtle changes about control medication compliance, which pediatric patients could not recognize:

PRB8 K-P "Well, basically he took his medicine on a regular basis. It's the same as before."

PRG4 K-P "Well. It's pretty much the samebut, she is more consistent."

Overall, the action of receiving/answering the text messages worked as a reminder that might change medication compliance, could lead to better health outcomes.

6.3.3.2 Theme 2: Change in Communication

Receiving/answering the text messages seeded conversation to various stakeholders. The pre-survey showed that parents usually initiated conversations about asthma before having the intervention. After children received the text messages, they tried to initiate conversations. They asked detailed questions about their asthma. Primary caregiver perceived the difference:

> *PUB1 K-C "It was very good. When I didn't mention anything about his asthma, he actually came to me with questions. He asked detailed questions. It wasn't just like mommy I'm sick...why am I sick? It was more related to his asthma why he has things and how to fix it."*

The text messages increased conversation about asthma between children and caregivers. It generally changed the frequency of conversation:

> *PUB5 K-P "We had more conversations about his asthma because the questions that he didn't understand, and he asked me the questions that he said you guys said it was wrong he would ask me."*

The SMS service broadened the scope of communication. The conversation usually had been between children and primary caregivers (usually, mothers). Children attempted to share the information with those who usually had not done. Specifically, the knowledge questions made children reach other caregivers, who they usually did not discuss asthma with:

> *PUG5 QK-P "I was saying once a week. I heard text messages she was finding out the information she want to share with family."*

> *PRB11 QK-P "It made him discuss with his dad a lot because Dad doesn't know a lot about asthma. So kind makes dad more aware too."*

Even though a pediatric patient initialed communication, sometimes the primary caregiver wanted him/her to be independent, and was satisfied with the intervention, which decreased parent's direct involvement:

> *PUG8 K-P "She told me hey look at this. She didn't share all of them with me. But, when she was unsure of her answer. She wanted me to look at it, I just told her 'no! you need to answer it if it's wrong it will tell you'. So I was happy to something she can do independently without intervention for me."*

A rare case showed that sometimes the interaction with the SMS service made children talk about their asthma less than they did before because they were getting better after using the SMS service:

> *PRG8 QK-P "I guess she and I didn't communicate a lot cause she's gotten better. I didn't hear any complain."*

The SMS service facilitated communication not only with caregivers, but also with healthcare providers. When children had the follow-up visits, the SMS service deepened understanding of what a doctor was saying or children had more questions about their asthma. The SMS service increased patient's knowledge and understanding of their asthma:

> *PUG8 K-C "Uh, well, I can understand what he is talking about now. like before I didn't understand some of the questions."*

> *PUG5 QK-C "It (conversation) changed because now I understand about the asthma"*

> *PRG15 K-C "(It) makes me have more questions to the doctor"*

Thus, receiving the knowledge questions where children did not know the answers triggered conversation with others in the family. It also changed the quality of interaction with their doctors.

6.3.3.3 Theme 3:Change in Asthma Knowledge

Children expressed diverse experiences about gaining knowledge through the SMS service. There was both positive and negative feedback on the current SMS service (knowledge service).

Both children and parents agreed that there was increased knowledge, which made them feel better. Our feedback about their answer was one of satisfying factors in the SMS service:

> *PRG4 K-C "(I)feel better like I knew what I was doing. Cause I think that I got fewer wrong which maybe feel better."*

> *PUB2 QK-C "It will tell me something I probably didn't know before. I will probably say 'unsure' or 'I'm not sure what it is', but it did help me."*

> *PRG15 K-P "It's been very informative. There have been a couple of times we had previous assumptions about things changed. She's answered the question wrong. It sent the correct information. And there has been a couple of questions that we had one belief, and the text message corrected what we had previously thought."*

> *PUG8 K-P "She did well manage her asthma. I think she understands better now..what things might cause triggers. I just don't think she even knew what asthma meant before."*

The knowledge questions were relatively easy for older children. However, "easy" did not necessarily mean that participants were unsatisfied with the questions. These

"easy" questions helped them reconfirmed their knowledge. The repeated manner of sending knowledge questions reinforced their knowledge:

> *PUB2 QK-C "It's pretty easy because I already knewI mean some of it. Chihuahua (question) I know that because I'm not allergic to it. It won't trigger to any my respiratory problems. Some of them, I wanted to answer. Like I already knew answersbut I was like, yes! this is great. I wanted to know this is right."*

> *PUG8 K-C "(I'm) very confident with my answers. It was very easy after they started repeating the questions."*

However, some other children were unsatisfied with the easy questions, so they would like to receive more difficult questions:

> *PUG6 K-C "Some of the questions are really easy for asthmatic patients."*

> *PUG1 QK-C "If you are ten years old with a cell phone it might be hard questions, but to me..it was easy."*

On the other hands, younger children thought the questions were too difficult to answer:

> *PUB11 K-C "It was a little bit difficult (to answer it), but I am fine with that since they gave me the correct answers."*

> *PRG15 K-C "Some of the question I didn't know..because I've not been really told about."*

> *PUB11 K-P "I think that some of the questions that were asked him. He didn't understand it, but then he understood it. You know alternative asthma medicine is better or not better. So ye.. he was little confused, so I think he guessed it and then the answer came through."*

Overall, knowledge questions increased patients' knowledge. However, it had issues regarding the level of difficulty depending on the knowledge level of pediatric asthma patients.

6.3.3.4 Theme 4: Change in Asthma Awareness

Questions about their asthma symptom/management via SMS raised awareness about asthma. When children answered questions about their symptoms/management (the Query version), they tried to recall what they had or did for asthma management. Answering questions about asthma symptom/management helped children track what they did or what happened:

> *PRB4 QK-C "Umm, I think I thought about what the problems I was having more if any problems. I like what can I do to get this better... I think after the questions may be I feel lucky I don't have any problems since the study."*

> *PRG10 QK-C "In the past few days, has this, this, or that happened, you know. I would think about it, and it really let me think about it. Wow! that really did happen. You know I didn't even think about that or realize (without the questions)."*

From the perspective of the primary caregivers, they felt that their children knew what symptoms the had:

> *PRB11 QK-P "It made him more aware. He did a lot better it increased awareness."*

None of participants, who only had the knowledge questionnaire, mentioned awareness change. Thus, the only questions about symptom/management might help them to recall what they did or what issues they had.

6.3.3.5 SMS Service

Pediatric asthma patients provided a variety of feedback about the SMS service. Here, I define two separate findings.

First, texting has become an essential part of teens' lives, so using text was not another burden for them. The way to interact with the text messages was one of successful factors to maintain high response rate. They also appreciated the amount of messages and the way they could answer the questions:

> *PRG8 QK-C "It was easy. What I needed to do was just type the letters."*

> *PRG10 QK-C "It was very simple, and it didn't take much at all to answer it."*

> *PUG8 K-C "(It's) very easy to text. I didn't need to type whole letters (TRUE or FALSE)."*

Second, however, most of the children mentioned the repeated questions in the knowledge service. Since we sent out the same questions every month, children, especially those who had the follow-up visits later, felt bored and annoyed. They would like to have a variety of questions. Despite this problem, children were good at answering the questions according to the response rates: :

> *PUG15 K-C "Some questions stayed the same. Is it like the same questions? I'd like to change a little bit."*

> *PUG8 K-C "I would say more questions we don't just keep doing the same questions over and over and over"*

> *PUG1 QK-C "It was like ask me questions start back over ask me the same question. And I will be thinking like I answered this question two weeks ago. But I still answer it anyway."*

Thus, texting itself is an appropriate method for distributing information in the pediatric patient population. However, we need to find out better strategy to provide the information in terms of content.

6.3.3.6 Physician's Dashboard

Two pulmonologists shared their overall experience of the Physician's Dashboard and patient management during the study.

The Physician's Dashboard was not useful enough to support patients' management since P1 did not have enough participants in the dashboard or they received false positive alters:

> *P1 "It was ok but not good. I feel like there were so few of my patients on it, so I kind of forgot how to use it between the patients. But when I got the email alerts then it was easy to get back on the dashboard. It was a little bit cumbersome to figure out why it was alerts. I could figure out after few trials... If I have many patients, it might be better using any software. Last thing that was not a very practical experience is that my patient kept coming up positive of using too many albuterol. When we would call and talk to his parents, even we saw him once, and he was doing fine. We couldn't figure why he kept telling you guys he used albuterol. He may not has been honest with texting."*

False positive alerts from a patient discouraged P3 to use the dashboard:

> *P3 "Once in a while, I would get the email notifications from two of my patients. I have to be honest. I didn't take them too serous because I would get the notice every single day for a period time. I learned when I saw that patient. They didn't really understand what they were reporting. He was actually reporting his inhaled steroid not his emergency oral steroid.*

After he was corrected, I didn't hear anything more on the dashboard...So it pointed out more misunderstandings than what I perceived to be true emergency asthma exacerbation."

Positive perspective of these false positive alters was inter-personal communication change in the patient's follow up visit:

P3 "I tried to re-educate about the purpose of each his medicine, and had him repeated back to me."

They were satisfied with email as a medium to deliver information because it is asynchronous. However, P1 expressed concern about protected health information over email:

P1 "Yes, it(email) is not urgent enough that I need to text and phone call. When you design a whole system, you just have to make sure that you know once any patient data goes to email that's whole different HIPPA level."

P1 used the button to send his nurse messages for following up with the patient when he received alerts. However, P3 did not use the function:

P1 "What I did is open up the software(the Physician's Dashboard) to see why we got the alerts and then I send messages to my nurse to call the patient to know what's going on."

P3 "...the email alerts, sometime I am not looking at email until late in the evening. And by then hopefully either he's already gotten help or he's already been sleeping in bed peacefully."

They thought that using the dashboard had positive impacts on their practices and their patients though they had the issues above:

P1 "It was an easier way to communicate with the patient...much easier so far. it's a great way to keep in touch."

P3 "I could identify more clearly and what his confusion was and just begin to discuss that straight away rather than having to investigate."

The pulmonologists suggested how we could improve the current dashboard system in three folds. First, the dashboard can be targeted to different healthcare providers such as physician assistants(PA) or nurses. Second, one-page summary can be printed out just before patient's appointments. Finally, specific information should be provided when a patient has issues:

P3 "That (information) doesn't necessarily have to come to me. That can come to one of my nurses or my PA. So that they can reinforce the education 'you need to use albuterol this time.' "

P1 "At the visits, we probably need to be able to print out some kind of data for the last three months cause it usually has been three months since I saw them...umm you know I asked him how has it been going for last three month. They don't remember the ups and downs three months ago. So If we got a graph with the symptom scores each day, something like that. That will be really helpful."

Since the system provided only basic information, P3 did not think that she had enough information to understand what happened to their patients. She would like to have detailed information about their patients when they had issues:

P3 "Just because they have taken albuterol. It doesn't mean they necessarily need medical intervention from a care provider. If it's 120 degree outside, you gotta need albuterol. That's probably true no matter what he

had done...I wouldn't contact them directly that point either (emergency room) because I am presuming that whoever's care under they will follow up with me...I want to know how many times and what circumstances they're needing to take a rescue medicine. I want to know that if they did take oral steroids or sick medical attention, what they do before then. In case there was something we could have done to prevent them needing oral steroid or needing medical attention. What triggered it? What do they do to response to it? Have they learned? ok 'when I start coughing I need to take albuterol', or did they not take albuterol when straight to oral steroid or straight to an emergency room? Clearly, I need to work harder on teaching them how to manage their exacerbations."

Interviews with the pulmonologists show other requirements, which I could not identify in the exploratory studies. Including other healthcare providers as a user is crucial for a promising dashboard design.

6.3.4 Observation

For the second deployment, I was staying at the doctor's office as a researcher. Here, I describe my observation of current practices to suggest implications, which are related to issues I found in the previous sections.

When a patient visits the doctor's office, we can view the visit into three phases:

1) *Check in* – a patient and caregiver check in at the front desk. In this phase, the staff changes the status of the patient in the electronic health record (EHR) into 'check-in' and collects or confirms their insurance information. If necessary, the staff also collects payment for the bill.

2) *'Exam' Started* – when a nurse finds a patient who is in the 'check-in' status, the nurse goes to a waiting room, and calls the patient. At that time, the nurse changes the status of patients from 'check-in' to 'start'. The nurse starts measuring

height and weight. After that, the nurse brings the patient/caregivers to an assigned 'exam' room. At that time, the nurse puts a checklist sheet, which includes basic information and a checklist for check-out, into a paper holder attached to the door of the 'exam' room. The nurse pushes a violet button, next to the door, to call a specialist to conduct the pulmonary function test (see Figure 28). The violet button is turned on steady. In the room, the nurse asks the patient/caregiver detailed questions about patient's condition. While they are talking, the specialist comes into the room and brings the patient to the pulmonary function test room along with the paper from the holder. The specialist pushes the violet button again so that the button is blinking. When the nurse finishes the conversation, he/she comes out. After the pulmonary function test is done, the specialist brings the patient back to the room with the checklist sheet and a pulmonary function test sheet. He/she put the two sheets in the holder, and pushes a white button to turn on the button steady. During the process, a pulmonologist meet other patients, or takes the two sheets from the door and checks the EHR to review the patient. After the review, the pulmonologist pushes the white button again to make the button blink and enters the room to ask the patient/caregiver detailed questions about the condition and write a prescription if necessary. During the conversation, the pulmonologist can push yellow or red buttons to call someone for a flu shot or education. When the pulmonologist finishes the conversation, he/she pushes the white button again to turn off so that it indicates the room is empty.

Figure 28: A paper holder (top) and button interface (bottom).

3) *Check out* – At that moment, the patient and caregiver leave the room and head to the front desk to check out. When all paper work is done, the status of the patient changes into 'check-out'.

6.4 Discussion

In this section, I draw across the findings of two deployment studies to reinforce that the simple SMS service is an intervention that raises symptom awareness and increases knowledge for pediatric asthma management. This intervention had positive effects on pediatric patients' health outcomes, as shown by both physiological and psychological measures. Interviews revealed how and why the intervention worked. In particular, patients with public insurance had better improved results than patients with private insurance. I discuss the similarity of difference of two deployment studies, issues uncovered in the second deployment, and how such challenges may be addressed. I provide some implications for design of future communication systems for pediatric asthma patients and healthcare providers.

6.4.1 The Similarity and Difference of Two Deployment Studies

I confirmed that the pediatric asthma patients who both answered questions about their asthma symptoms/management and received information about asthma showed improved health outcomes, as evidenced by pulmonary function and quality of life (only patients with private insurance) as compared to the control groups. Additionally, children with public insurance in the knowledge group had better health outcomes as evidenced by pulmonary function, as compared to the control group while children with private insurance in the knowledge group did not have (see Table 20 to compare between the first and the second deployment). I can infer this result from the difference of initial pulmonary functions between patients with public and private insurance. The initial pulmonary functions of public insurers were lower than private insures' (FVC%: $t(40) = 3.32$, $p = 0.001$, FEV1%: $t(40) = 3.31$, $p =$

Table 20: Comparison between the first and the second deployment.

	First Deployment		Second Deployment			
Duration	11/3/10 ~ 12/22/11		10/26/11 ~ 5/9/12			
Group	*Query*	*Q & K*	*Q & K*		*Knowledge*	
Insurance	Most Private		Private	Public	Private	Public
Physiological	No	Yes	Yes	Yes	No	Yes
Psychological	No	Yes	Yes	No	No	No

0.001, FEF25-75%: $t(40) = 2.21$, $p = 0.017$).

On the other hand, only patients with private insurance in the Query &Knowledge group had improved quality of life while patients with public insurance did not have. I can draw two inferences from this result. First. independent determinants of PAQLQ vary according to asthma severity [110]. Lung function might not be an independent predictor of quality of life in public insurance population. Thus, this explains why the patients with private insurance had improved quality of life since they had better lung function than patients with public insurance had. Second, previous study showed that asthma severity, socioeconomic status, and racial/ethic group explained 67% of the variance of quality of life [9]. This study shows that socioeconomic status remained significantly associated with quality of life. Thus, socioeconomic status is still a strong factor as determinants of quality of life compared to the technology intervention, which impacted only pulmonary functions. Third, three to four months might not be enough period to change quality of life for patients with public insurance.These factors can explain why PAQLQ did not change for low-income patients. We need to identify what factors can affect their quality of life.

I revisited the perspective of sustainable technology in the context of the clinical setting. The SMS service was able to meet the level of response rate I observed in the first deployment. The SMS service had the similar response rate 85.6% (83% in the first deployment), sustained over the 3-4 month duration of the second study.

The other challenge was to facilitate current practices for pediatric asthma management. Since children visit the physician at most three or four times a year, physicians rely on patients' or caregivers' recall to understand patients' symptom/management history. My SMS study showed that children were willing to provide continuous data about their symptom/management. My results reconfirmed that the "rolling ATAQ" scores had concurrent validity since the rolling scores at the final visit were significantly correlated with the standard ATAQ scores administered during the follow-up visit.

In the first deployment, the fact that the Query & Knowledge group received more messages than the Query group might impact on the results. However, the finding in the second deployment that the Knowledge Group with public insurance showed significant pulmonary function improvement compared to the control group supports the suggestion that health improvements were not simply due to the fact that the Query & Knowledge Group received more messages. Various factors such as socioeconomic status, severity, and ethnicity can influence the performance of intervention.

6.4.2 Issues with the SMS service

While the service impacted pediatric asthma management, I uncovered two issues with the SMS service. First, repeated messages bothered some participants. Second, older children wanted to have more challenging questions. Since the SMS service had only 15 knowledge questions, participants experienced repeated questions after a month. Older children, in particular, felt that the questions were easy. However, none of the participants mentioned that the repeated asthma symptom/management questions were problem. While younger children thought the knowledge questions were a bit difficult, others would like to have more practical or challenging knowledge questions about their asthma.

Thus, the SMS service needs to have a variety of questions and have a different scheme to send the questions, so that the children do not receive repeated questions. Additionally, the SMS system can adjust the degree of difficulty of questions, based on the age or level of knowledge of the participants.

6.4.3 Issues with the Physician's Dashboard

Another goal of this study was to facilitate or improve the communication between patients and healthcare providers. However, the current dashboard design did not meet physician's expectation. I identify two issues with the current Physician's Dashboard.

First, the log data showed that the physicians did not frequently log into the Physician's Dashboard to review their patients' status compared to the first deployment. This was because patients generally managed asthma well, so the system did not send many alerts. Another reason is my experiment design (RCT) did not allow pulmonologists to have many participants in the Query & Knowledge group (maximum number was 3 patients in the Query & Knowledge group).

Second, the PRA data indicated that there was no perceived change of the quality of interaction between the first visit and the follow-up visits in general except Affective Index in patients with public insurance. Lack of the dashboard use, dashboard design, inappropriate instrument, which was designed for adults, might cause the result.

I can infer three reasons why the Physician's Dashboard might not affect the current practice. First, PA, who was not the user of Physician's Dashboard, met many patients during their follow-up visits. Second, as I already mentioned, the number of patients who were in the Query & Knowledge Group per pulmonologist was small. Thus, the dashboard could not be well integrated into the current practice. Third, other doctors thought that the system was not useful in the current design form. In the next section, I will describe opportunities to improve the current Physician's Dashboard based on my observations in the next section.

6.4.4 Future Physician's Dashboard

There are lessons to be drawn from the results of the dashboard that can be applied to future dashboard system, as well as current practice observation that can help address some of the challenges that using the Physician's Dashboard in this study.

I consider the Physician's Dashboard in light of current practice in the doctor's office. Various stakeholders have different roles in these practices. The Physician's Dashboard can be renamed 'The Provider's Dashboard'. This means, as with the EHR, healthcare providers (not only pulmonologists but also midlevel providers and nurses) can have access to patients' status anytime and anywhere they want. For example, the system can send alerts to nurses to follow up with patients, because nurses are usually the ones to call their patients.

Another improvement of the dashboard can be creating one-page history sheet when a patient visit the doctor's office. As I already described the process of the visit, the system can print out one-page summary, and a nurse can put it in the holder before a pulmonologist or a PA enters the room. So when they usually check the status of patient with pulmonary function test sheet, they can review the history of asthma management with the summary sheet from the SMS service.

To provide healthcare providers with detailed information about patients, we can modify the scheme of the current SMS service. For example, when a patient replies with yes to a specific question, the future SMS service can send a follow-up question to ask detailed information.

6.5 Conclusion

SMS is ubiquitous, easy to use, and inexpensive. My two deployment studies demonstrated efficacy with improved health outcomes for a pediatric asthma population. Given that other standardized questionnaires could be implemented via SMS, this approach may be relevant to other chronic conditions. An important strength of

our current approach is that it can be easily adopted and maintained by patients and healthcare providers. The system could be built in such a way that healthcare providers could customize the database of text messages created for their patients. In short, SMS usage is ubiquitous and thus can be embedded into clinical practice.

Specifically, I found a high rate of SMS adoption among patients; high and sustained response rate during the period of the study, similarities and differences between the "rolling ATAQ" and the standard ATAQ questionnaires. These results indicate that SMS may be a cost- and labor-effective way to keep physicians updated about their patients' asthma status between scheduled visits.

In this study, I focused on pulmonologists and pediatric asthma patients, but my findings indicate that communication between pediatric asthma patients and other healthcare providers could be affected by the SMS Service. The second deployment introduced challenges with the integration into current practices regarding the Physician's Dashboard. Overall, the SMS service appears to represent a promising direction for clinical communication technologies, once modifications to the system help ameliorate some of the concerns discussed above.

CHAPTER VII

DISCUSSION

In this section I discuss the findings and lessons from the first and second deployment of the SMS service and the Physician's Dashboard. First, I discuss the findings across the two deployments by examining pediatric asthma management through the lens of the Health Belief Model and its limitations. Second, I compare my two deployment studies with other studies using SMS to support chronic illness. Third, I discuss why the intervention improved health outcomes. Finally, I provide an agenda for future work in supporting the management of pediatric chronic illness.

7.1 Using the Health Belief Model to Understand, Design and Assess Technology Intervention

My intervention was aimed to help the management of pediatric asthma. The management requires: 1) patients' skills to meet their subjective goals; and 2) improved health outcomes to satisfy patients, caregivers, and healthcare providers. However, the holistic understanding of management is too broad to obtain a satisfactory result from just one study. I employed the Health Belief Model (HBM) to design and evaluate the system in order to shape answers regarding the manner (how?) and purpose (why?) of technology intervention usage. Theories can guide the search for why the interventions do or do not impact health outcomes, provide insight into how the interventions are used, and identify what should be measured in an intervention evaluation [86]. For example, Consolvo et al. proposed design strategies to support people who want to be proactive [33]. They used theory to extend their design goals to address social characteristics. Their system showed the possibility of maintaining

a physically active lifestyle and validated their strategies. Thus, using theory is sometimes helpful to uncover issues, design the elements of an intervention, and assess the elements.

7.1.1 Health Belief Model (HBM) for Analyzing Intervention Impacts

In this section I will recap the concepts in the HBM, which is a theoretical framework for understanding health-related behavior. This model includes primary concepts to explain why individuals will take action to manage their health [71]. The primary concepts are:

Perceived Susceptibility One's subjective perception of the risk of contracting a condition.

Perceived Severity Feelings concerning the seriousness of contracting an illness vary from person to person.

Perceived Benefits Beliefs regarding the effectiveness of the various actions available in reducing the disease threats.

Perceived Barrier The potential negative aspects of particular health actions.

Cues to Action Internal or external triggers for actions.

Modifying Factors Variables influencing perceptions, which include knowledge and sociodemographic factors.

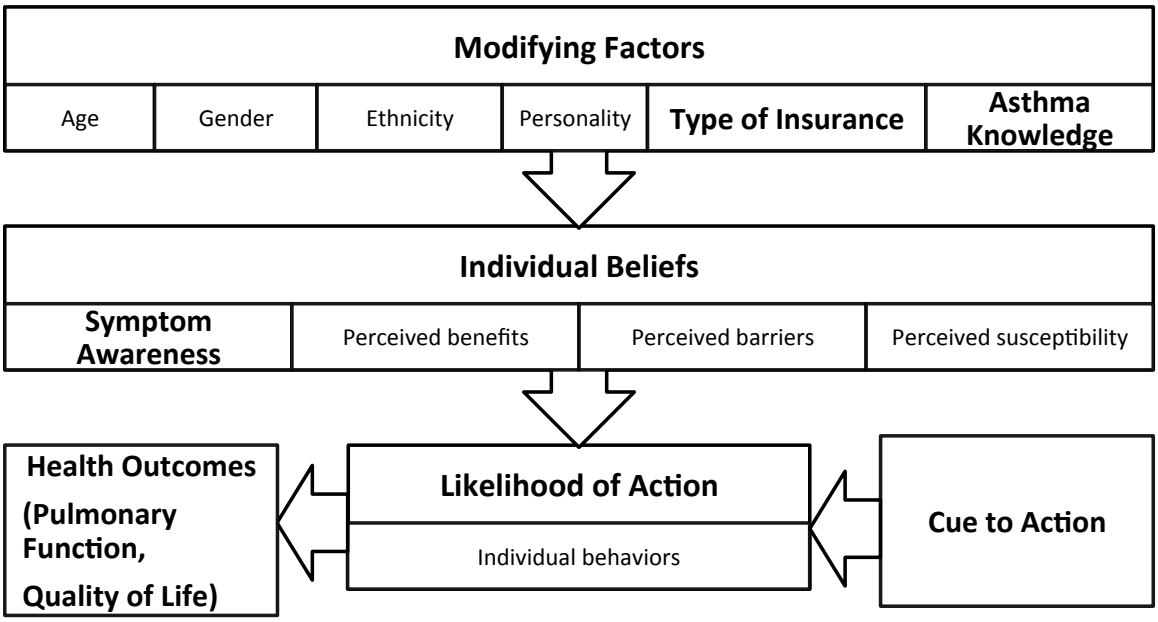


Figure 29: Health Belief Model constructs used in the first and second deployments [13, 130, 131, 71].

For the first deployment study, I explicitly addressed perceived severity (symptom/management awareness) as an individual belief and asthma knowledge as a modifying factor. This is because knowledge acquisition is crucial for successful treatment of asthma [156], and correctly-perceived severity of asthma was helpful to compliance with a medical regimen [13]. However, I did not measure change in perceived severity in the first deployment. In the second deployment of the intervention, I included type of health insurance as an additional modifying factor. Since the post-hoc analysis of the first deployment showed baseline difference of health measures based on type of health insurance, I examined whether type of heath insurance could be a predictor of the degree of an intervention's effects, and measure change in perceived severity in the second deployment (see Figure 29).

I designed the intervention to increase knowledge through questions about asthma and to affect perceived asthma severity through symptoms/management questions. This lead to improved physiological and psychological outcomes as a result of change

in behavior. My interview data show that patients in the experimental groups indicated change in adherence to medication regimen. However, the first deployment study showed that using only one construct (individual belief) in the HBM did not improve health outcomes. For example, patients, who answered only questions about symptoms/management did not have improvement in health outcomes.

When I looked at the results of the second deployment, I could interpret the similar results differently. As I expected, patients with private insurance in the second deployment had the same results as the patients in the first deployment. However, patients with public insurance in the two intervention groups both had improved pulmonary function outcomes. I can infer the reason that health insurance as a proximal socioeconomic status affected the degree of intervention's effects in two ways. First, the socioeconomic status affected the difference of baseline health measures between the patients in public insurance and private insurance [3]. Other research already found these baseline differences [109, 29]. Second, socioeconomic status could impact the degree of pulmonary function and quality of life improvement differently. For example, while the patients with public insurance had improved lung function, they did not have improved quality of life. When we design technology interventions, we should consider which health outcome we are targeting and which population we are targeting. A longitudinal study may be required to determine the change of quality of life for patients with public insurance. Without the HBM, I might not have found out how the health insurance type affects the effectiveness of the intervention.

The HBM provided a useful lens for understanding the interventions with pediatric asthma patients and pulmonologists because it explains distinct constructs, which affect health-related behavior. After analyzing data from the two studies, I found that other HBM constructs could be inferred from the intervention without any intention. First, the interviews suggest that the messages could serve as a "cue to action". For example, receiving/answering the text messages lead patients to take

their medication. They already knew taking medicine was helpful for their asthma management, but they sometimes forgot to do so. Receiving/answering the text messages were one of cues to action, which I did not intend to design. Second, knowledge questions in my studies might teach perceived susceptibility, benefits, and barriers. I viewed knowledge questions as a modifying factor. However, in future work we can view and design the knowledge questions as an education tool to change different individual beliefs since knowledge of all perceived beliefs can be crucial for successful interventions [65]. We can design our knowledge questions to be fitted into each belief for further studies. One of the knowledge questions is "people with asthma should not exercise". This question can help a patient understand how exercise is good for the lungs.

One of missing elements in this study was the measurement of health-related behavior change as a result of the intervention. I measured physiological and psychological outcomes directly without measuring objective change in health-related behavior. In future studies, we could research compliance with medication regimen using a special medication (e.g. inhaler with a counter), prescription refills, the number of uses of rescue medication, and other objective/subjective measures. This kind of data will help us link actual change in behavior and health-related outcomes. We can also identify how a technology intervention works, and which behavior change leads to actual health-related outcome improvement.

7.1.2 Other Theories for Understanding Pediatric Asthma Management

The HBM is not the only theory for pediatric asthma management. Many other theories have been used in research. Researchers use theories is to help them identify effective components in an intervention [27]. These theories are: 1) models of health, illness, and sick-role behavior; 2) social learning theory; 3) models of physician-patient relationships; 4) self-regulation model; 5) communication theory; 6) ecologic theory,

and etc [23]. Interventions based on the theories have been effective in reducing symptoms, emergency room visits, and hospitalizations [27]. However, they did not measure physiological outcomes or show improved results.

For example, Joshi et al. investigated the feasibility of a computer-based interactive asthma educational tool in a pediatric emergency department. They designed the educational tool based on three theories; behavioral theory, cognitive learning theory, and humanistic theory. They used behavioral theory to explain how change in behavior manifested learning, cognitive learning theory to provide individualized education, and humanistic theory to evaluate participants willingness to learn. Unfortunately, they showed only the feasibility of the tool not improved health outcomes [77]. Thus, we should rationalize why we use a theory and the link between the theory and results obtain.

For future research, we can combine the HBM with other theories. For example, the Transtheoretical Model (TTM) might be a candidate. TTM uses stages of change to incorporate processes of change from across major theories of intervention [125]. My data showed that different pediatric asthma patient groups based on insurance type had different levels of knowledge about asthma. The level of knowledge about barrier, benefit, susceptibility, and severity might affect which stages of change in TTM a pediatric patient is in. Patients in different stages might have different heath beliefs. Thus, we can design and evaluate the different HBM components of a technology intervention based on the stage of TTM, to which a pediatric patient belongs. This approach will help maximize the effectiveness and support the sustainable use of the intervention over prolonged periods of time.

Overall, using the HBM helped me frame the intervention to support pediatric asthma management. It uncovered findings I did not expect and provided a guideline for a possible future revision of the SMS service and Physician's Dashboard. For future work, we should consider using different theories or combining theories to

design/evaluate a technology intervention in a different context (population, type of disease, etc.).

7.2 Interventions Delivered by SMS

In this section I compare my deployment studies and two clinical studies to identify strengths and weakness of my study since these studies are related to my study in terms of either investigating asthma management or dealing with pediatric patients. My study was not the first study to use SMS for supporting chronic illness. SMS has been a popular communication intervention for health behavior change. This service is available to pediatric population, can be tailored messages, and provides asynchronous instant delivery [47]. SMS was used for both preventive health behavior and clinical studies [152, 49, 149, 52, 77, 49, 126, 120, 36, 76]. Diabetes self-management has been popular in clinical studies using SMS [95, 49, 126].

Ostojic et al. conducted a 16-week randomized controlled trial to assess SMS as a means of peak expiratory flow (PEF) monitoring with 16 young adult participants with asthma [120]. In this study, participants sent daily PEF measures to a doctor and received advice. The similarity between this study and my study is that the intervention showed improved health outcomes. This study reduced PEF variability, and slightly improved FEV1 (statistically significant) in the experimental group. The main differences between this study and my study are: 1) SMS Initiation - participants initiated the text messages in this study while the SMS service initiated queries in my study; 2) Contents - Ostojic's study had individualized feedback (once a week) from a specialist while my SMS service did not provide participants with feedback other than knowledge answers. Two factors arose to inform the design of future research. First, the mode of intervention initiation might impact the outcomes of the interventions and compliance with the services. I could not find clear differences in outcomes based on the mode of intervention initiation. Future research should investigate how specific

SMS characteristics (e.g. the initiation of SMS communication, tailored contents) affect behavior and outcomes. Second, weekly tailored-feedback can help pediatric asthma participant engage in asthma management. This might increase the response rate of a study and the effectiveness of the intervention in my study. However, PEF reports might not be a good solution for pediatric asthma patients since PEF reports from that population are unreliable [84]. Simple SMS studies (not individualized) like my study may lead to improved outcomes.

SMS studies have been used to address management of other chronic conditions like diabetes. Another study used SMS for pediatric diabetes self-management [49]. This study is relevant to my study in terms of dealing with pediatric patients with chronic conditions. The study design was RCT for 12 months and had 92 pediatric patients with Type 1 diabetes. The intervention called 'Sweet Talk' was a text message service, which delivered a 'social cognitive theory' based intervention. Sweet Talk sent scheduled messages such as weekly reminder of the goal set in clinic, tips, information, and reminders to reinforce the goal. The system had more than 400 messages. This intervention showed self-efficacy and self-reported adherence to insulin regimen (Psychological outcomes). However, Sweet Talk did not improve HbA1c (Physiological outcome). The similarity between this study and my study is targeting to pediatric patients, and adopting a theory to design/assess the interventions. Major differences are: 1) The frequency of messages - Sweet Talk sent more than 4 messages per a day while my system sent out up to one message a day. However, the Sweet Talk study did not report detailed information about message interaction or frequency. Since Sweet Talk was the one-way communication from the system to patients, they did not report any response rate; 2) No physiological outcome - Sweet Talk affected no physiological outcome but psychological outcomes while my system showed both improvements. The way they chose to allow the participants to interact

with the text messages might cause the difference because another SMS study targeted to adolescents with type 1 diabetes had improved HbA1c [126]. Participants in this study sent daily blood glucose level, insulin doses, and carbohydrate intake via a GPRS (not SMS). They received one text message with individualized feedback text. Thus, the two-way interaction through a technology intervention can be more effective than one-way interaction. Additionally, the asthma medication regimen is much simpler than diabetes, which requires taking more medications. This might impact the way the SMS should be delivered.

Regardless of the differences and limitations, our common findings suggest that text messages can offer a means of supporting chronic diseases and can show the feasibility and utility of text messages. Further studies should be conducted to identify links between interventions, psychological outcomes, and physiological outcomes with diverse format of text messages, duration, and the mode of SMS initiation.

7.3 Why the Intervention Improved Health Outcomes

In this section I will discuss why my SMS service and Physician's Dashboard improved health outcomes. Since I used the HBM, which explains how/why behavior changes, to design the intervention, I will describe relationships between health behavior and outcome first.

Technology intervention for health management is usually targeted to health behavior. The definition of health behavior includes the actions of individuals, groups, and organizations as well as improved coping skills and enhanced quality of life [123]. Gochman also suggested that both observable action and measurable mental states can be health behavior. He defined health behavior as "those personal attributes such as beliefs, expectations, motives, values, perceptions, and other cognitive elements; personality characteristics, including affective and emotional states and traits; and overt behavior patterns, actions, and habits that are related to health maintenance,

to health restoration, and to health improvement [53]."

When a technology intervention change health-related behavior, but physiological outcome is not improved, we should examine the link between behavior and outcome or the ways in which we measure behavior and health outcome [86]. Fortunately, my study showed behavior change (quality of life) and improved health outcomes (physiological outcomes).

There are possible reasons why health outcomes were improved. First, I chose SMS as the appropriate medium for pediatric patients. A child living with asthma can have access to SMS. Second, simple interaction such as typing 'Y' or 'N' allowed children's engagement of service. The way in which patients interacted with the service increased the response rate. Third, high response rate can lead to engagement in asthma management, which increase compliance with medication. However, we need to adopt these strategies for different age groups. For example, SMS is not probably a good candidate for elderly people. Additionally, prolonged engagement should rely on not only interaction with the SMS service but also increased quality of interaction with a physician. The Physician's Dashboard can have an important role at this stage.

Overall, my specific design scheme can work in the specific setting. However, we should think about a different approach to apply a similar service to different illnesses or populations.

7.4 Future Directions in Using SMS for Supporting Pediatric Asthma Management

Despite successful results from my two deployments. There are still open research questions. In this section I discuss the opportunities along two directions. First, I will describe how the HBM could be used to design and assess components in ubiquitous communication technology for chronic disease management. Second, I will discuss study design changes that present opportunities for addressing some of the limitation

of my work.

7.4.1 Addressing Missing Constructs of the HBM

Carpenter recommends that testing complex versions of the HBM may offer greater predictive power [25]. However, I tried to address only knowledge, perceived severity, and socioeconomic status in the HBM. I did not investigate other constructs, which might affect the outcomes and have significant relevance in health-related behaviors and health outcomes. If I could investigate each construct more thoroughly, I could identify which one to focus on in the context of pediatric asthma management. For example, knowledge intervention can be designed and categorized into the four beliefs in the HBM. Study design might adjust these constructs to maximize the effects of the intervention. Similar to other studies that often have missed cues of action [86], I did not explicitly design the intervention to address cues to action. Implicit (e.g., receiving text messages) or explicit (e.g., reminders) cues to action can be defined in the design of interventions. Thus, we need to investigate what cues to action can lead to improved physiological, psychological, or both outcomes.

Table 21 summarizes application examples based on my study. However, I did not provide evaluation examples since the HBM has limitations in the variability of the measurement of the HBM constructs [86]. Researchers using the HBM need to validate measures in future studies to measure the constructs that affect health-related behavior and outcomes.

Table 21: Application Examples of the Health Belief Model

	Application
Perceived Susceptibility	Individualize risk based on pediatric patient's characteristics
Perceived Severity	Specify the status of asthma and conditions
Perceived Benefit	Explain positive effects when taking action
Perceived Barriers	Correct misunderstandings
Cue to action	Use direct/indirect reminders and promote awareness

7.4.2 Addressing Uncovered Issues

7.4.2.1 Study Design

One question I did not address in my deployments is how the frequency of text messages can impact outcomes. For example, we might need to design dummy messages to adjust the frequency of messages across different study groups. However, it is difficult to design the dummy messages to be used as placebos, similar to those used in medical research, since participants can perceive the dummy messages differently. We should think about the role of placebos in technology intervention study adopting RCT. This will help clarify the effect of message frequency.

The two deployment studies lack generalizability because it was conducted in only one doctor's office. Specifically, the current practice of the doctor's office could affect the design implications. Thus, conducting research with different chronic illnesses in different places can help generalization of using the HBM to design interventions.

While studies that focus on health interventions have to balance the sustainability of use and the novelty of technology, my study was geared toward the sustainability of use. However, the duration of the current study ($3 \sim 4$ months) was not enough to see prolonged use of the intervention. For the longitudinal use of technology, many

researchers have tried to use a novel technological approach, which could offer flexibility in the design of a health management intervention [134, 124]. Tailoring messages are necessary for a prolonged study duration [47]. The results show that tailored interventions lead to greater improvement in behavior changes than do untailored messages. Similarly, although I had a response rate of 85% for $3 \sim 4$ months, tailored response messages may also lead to improved response rates for a longitudinal study over year-long periods of time. Since participant engagement in intervention is a critical factor for success, one future direction is to investigate the effects of tailored text messages in pediatric asthma research supported by SMS.

For prolonged impact of intervention, interpersonal communication between patients and pulmonologists can have an important role. Using the SMS service and the Physicians Dashboard sometimes influenced this communication. For example, when a patient had a follow-up visit, a doctor or a nurse taught them how to use rescue medication when they answered the question about rescue medication from the SMS service. However, I could not measure this effect due to the duration of the study. Perhaps higher quality of interaction with a physician at the follow-up visit leads to improved management in the next $3 \sim 4$ months period.

7.4.2.2 Target User

In the two deployment studies, I focused on pulmonologists and patients. The Physicians' Dashboard was not truly integrated into the clinical practice. Since my formative studies did not observe the current practice over a long period of time, we could not identify the subtle difference of role between pulmonologists, PAs, and nurses. Through my time working out of the doctor's office, I gained an understanding of the process of practices and the role of different healthcare providers. Thus, I might broaden the scope of target users for the dashboard to fulfill the requirements of each healthcare provider. Additionally, delivering information to different healthcare

providers varies based on their roles.

My findings in the previous studies indicate that parents could have benefited from having access to their child's SMS responses. My survey data shows that there was discordance between children and caregivers in terms of how often they talked to each other about asthma. Parents thought they talked with children about asthma more often than what the children thought. There was no correlation between children's and parents' perceived severity, which can affect pediatric asthma management [96]. Thus, future systems may address this issue and provide a channel for caregivers to understand their child's needs (e.g., a parents' dashboard).

Overall, the discussion presented in this thesis addresses only a small portion of the issues in specific practices. Different practices might have different issues, as well as numerous other contexts and solutions to explore.

CHAPTER VIII

CONCLUSION

Pediatric asthma management is challenging due to complex triggers, the heterogeneity of conditions, and the various degrees of stakeholder involvement. I investigated pediatric asthma in home and clinical contexts to understand how ubiquitous communication technologies can support pediatric asthma management. From the formative studies, I suggested design opportunities for technology to support pediatric asthma management that are based on three challenges: detection; a behavior plan; and compliance in home settings. To better understand the needs for technologies in pediatric asthma management, I conducted technology probes study to explore opportunities for improving asthma management. The results show understanding the consequences of context allowed asthma management that leads to changes in confidence levels and sense of control. However, the limitation of this study was focusing on only home settings. The role of healthcare providers should be considered in designing technology with features supporting children's asthma knowledge, symptoms, and their contextual information regarding asthma. To address some of these issues, I designed systems called the Physician's Dashboard and the SMS Service, which were intended to increase knowledge and awareness of symptoms. I found a high/sustained response rate and "rolling ATAQ" scores during the period of the study. These results indicate that SMS can be an effective way to keep physicians updated about their patients' asthma status between scheduled visits. My system demonstrated efficacy, with improved health outcomes and quality of life for a sample of pediatric asthma patients. However, my two deployment studies also introduced challenges with the integration into current practices in regard to the Physician's Dashboard. Overall,

the SMS service appears to represent a promising direction for clinical communication technologies, once modifications to the system help ameliorate some of the concerns.

APPENDIX A

ASTHMA SYMPTOM/MANAGEMENT QUESTIONNAIRE

Question ID	Asthma Symptom/Management Question	Weight
1	In the past 4 weeks, did you have wheezing or difficulty breathing when exercising? N=No Y=Yes/Don't know	0
2	In the past 4 weeks, did you have wheezing during the day when NOT exercising? N=No Y=Yes/Don't know	1
3	In the past 4 weeks, did you wake up at night with wheezing or difficulty breathing? N=No Y=Yes/Don't know	1
4	In the past 4 weeks, did you miss days of school because of your asthma? N=No Y=Yes/Don't know	1
5	In the past 4 weeks, did you miss any daily activities (such as playing or going to a friends' house) because of asthma? N=No Y=Yes/Don't know	0
6	Did you use Albuterol/Xopenex for quick relief more than 3-times during a single day in the past 1 week? N=No Y=Yes/Don't know	2
7	In the past 4 weeks, did you use Albuterol/Xopenex for quick relief more than 3 nights? N=No Y=Yes/Don't know	2
8	Have you had any problems to take controller medication every day in the past 4 weeks? (NOT for quick relief) N=No Y=Yes/Don't know	0
9	Are you dissatisfied with any part of your current asthma treatment? N=No Y=Yes/Don't know	0
10	In the past 4 weeks, do you believe that your asthma was NOT controlled? N=No Y=Yes/Don't know	0
11	Do you believe that you are NOT able to take your asthma medicine as directed? N=No Y=Yes/Don't know	0
12	Do you believe that your medicine is NOT useful in controlling your asthma? N=No Y=Yes/Don't know	0
13	In the past 4 weeks, did you use an oral steroid (Orapred, prednisone) to help treat your asthma? N=No Y=Yes/Don't know	3
14	In the past 1 week, have you been to the emergency room or urgent care for your asthma? N=No Y=Yes/Don't know	3
15	In the past 4 weeks, how many times have you been hospitalized because of asthma?	3

APPENDIX B

ASTHMA SYMPTOM/MANAGEMENT QUESTIONNAIRE

ID	Knowledge Question	Incorrect Answer	Correct Answer
1	Everyone's asthma is the same. F=False T=True	Not exactly, Everyone's asthma is not the same. In fact, people with asthma can have different symptoms and different triggers	Correct, Everyone's asthma is not the same. In fact, people with asthma can have different symptoms and different triggers
2	You will grow out of your asthma. F=False T=True	Not exactly, Children do not grow out of asthma. They are likely to have it for life, even if they don't have any symptoms	Correct, Children do not grow out of asthma. They are likely to have it for life, even if they don't have any symptoms
3	Moving to a dry climate will cure my asthma. F=False T=True	Not exactly, Moving to a new location may improve your asthma symptoms for a while but it will not cure your asthma	Correct, Moving to a new location may improve your asthma symptoms for a while but it will not cure your asthma
4	Asthma is "all in the mind". F=False T=True	Not exactly, Asthma is not in your head but some emotions like laughing, crying and anger can make you breathe rapidly and worsen your asthma symptoms	Correct, Asthma is not in your head but some emotions like laughing, crying and anger can make you breathe rapidly and worsen your asthma symptoms
5	You can catch asthma from someone else who has it. F=False T=True	Not exactly, You can't catch asthma from others. Triggers like pollens, molds, animal dander, dust mites and cigarette smoke usually cause asthma symptoms	Correct, You can't catch asthma from others. Triggers like pollens, molds, animal dander, dust mites and cigarette smoke usually cause asthma symptoms
6	People with asthma should not exercise. F=False T=True	Not exactly, People with asthma can exercise. In fact, exercise is good for the lungs. You should talk to your doctor about what exercise is best for you	Correct, People with asthma can exercise. In fact, exercise is good for the lungs. You should talk to your doctor about what exercise is best for you
7	Getting a Chihuahua can cure my asthma. F=False T=True	Not exactly, Having a Chihuahua will not cure your asthma. In fact, a Chihuahua may stir up asthma symptoms in people who have allergies	Correct, Having a Chihuahua will not cure your asthma. In fact, a Chihuahua may stir up asthma symptoms in people who have allergies

8	Asthma is not serious. F=False T=True	Not exactly, Asthma is a serious matter. People with uncontrolled asthma can be hospitalized or even die. But remember, most asthma deaths are preventable	Correct, Asthma is a serious matter. People with uncontrolled asthma can be hospitalized or even die. But remember, most asthma deaths are preventable
9	Asthma does not require medical treatment. F=False T=True	Not exactly, Asthma usually requires daily medicines to stop symptoms before they start. Use your daily controller medicines to prevent symptoms from occurring	Correct, Asthma usually requires daily medicines to stop symptoms before they start. Use your daily controller medicines to prevent symptoms from occurring
10	The only way to control asthma is to completely avoid all triggers. F=False T=True	Not exactly, You may not be able to avoid all asthma triggers but there are steps that you can take to help control your asthma like following your Asthma Actio	Correct, You may not be able to avoid all asthma triggers but there are steps that you can take to help control your asthma like following your Asthma Action Pl
11	Asthma medicines are unsafe because of steroids. F=False T=True	Not exactly, The steroids used in asthma controller medicines are very low doses of steroids. Research has shown that these low dose steroids are safe	Correct, The steroids used in asthma controller medicines are very low doses of steroids. Research has shown that these low dose steroids are safe
12	Alternative medicines are just as effective as prescribed medicines. F=False T=True	Not exactly, The effectiveness and safety of many alternative medicines is unknown. Alternative medicine should never replace prescribed asthma medicines	Correct, The effectiveness and safety of many alternative medicines is unknown. Alternative medicine should never replace prescribed asthma medicines
13	I can avoid symptoms of an asthma attack by using albuterol. F=False T=True	Not exactly, Albuterol does not prevent symptoms from occurring. It only relieves symptoms after they start	Correct, Albuterol does not prevent symptoms from occurring. It only relieves symptoms after they start
14	Continuous exposure to pets will decrease my allergies. F=False T=True	Not exactly, Continued exposure to pets will not decrease allergies. The best way to relieve symptoms is to remove the pet from the home or the bedroom	Correct, Continued exposure to pets will not decrease allergies. The best way to relieve symptoms is to remove the pet from the home or the bedroom
15	Smoking does not trigger allergy or asthma. F=False T=True	Not exactly, Smoking is a known trigger of allergies and asthma and should not be ignored. Other triggers include pollens, molds, animal dander and dust mites	Correct, Smoking is a known trigger of allergies and asthma and should not be ignored. Other triggers include pollens, molds, animal dander and dust mites

APPENDIX C

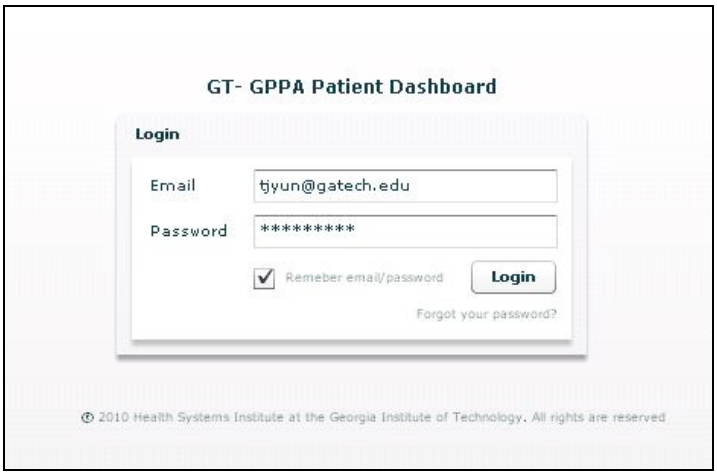
PHYSICIAN'S DASHBOARD MANUAL

Tutorial for training for the Physician Dashboard

This training session will take less than 20 minutes. It focuses on how to use the dashboard for monitoring your patients' asthma status.

Here is the dashboard's link. (http://research.hsi.gatech.edu/asthma/dashboard/)

A. Login



Screen 1. Login

In the first screen, you will be asked to log in our system. We will give you your id and password after this training session (Screen 1) OR via e-mail.

B. Bar Chart View of Patients (screen 2)

After you log into the dashboard, you will see the overview chart of your patients who are participating in this study (Screen 2).

FUNCTIONS

1. Backward/Forward buttons
The backward/forward buttons on the top left side helps you navigate a previous screen you have accessed or the next screen from the current screen.

2. Chart view button
The chart view button (next to the forward/backward buttons) allows you to go back to the overview screen when you look at other screens (e.g. a table view).

3. All patients button
By clicking the "All" button (next to the chart view button) you can see all patients in a table (Screen 3).

4. Search
You can search the database for a patient by patient's name or if you can not remember the patient's name exactly, you can enter any information you may remember. For example, if you type "k" and click search by name button, you can see all patients who have names that include "k". (e.g., Kelly, Derek)

5. Chart
This chart represents three groups based on GPPA's zone score, which is automatically calculated when a patient replies to an SMS query (based on a revised version of the ATAQ questions, For details see #7 in function section below). If you want to see one of the three groups, you can click on the bar itself (e.g.,

green bar, yellow bar, red bar). For example, if you want to see patients in the green zone, just click the green bar.

6. History buttons

At the bottom of the chart, you can see four history buttons to indicate the number of patients who answered "Yes" about rescue medicine usage, ER visit, oral steroid medicine usage, and hospitalization. For instance, if you want to check patients who replied about rescue medicine usage, just click the ER visit button. And then, you will see all patients who answered "Yes" with rescue medicine usage at least once.

Screen 2. Overview (Current Patient Status Chart)

C. Table view of patient list

You can view a list of patients by doing any of the following actions: searching patient data by name, clicking the "all" button on the navigation bar, clicking a bar from the chart, or clicking a button below the chart, you will see the patient list screen (Screen 3).

FUNCTIONS

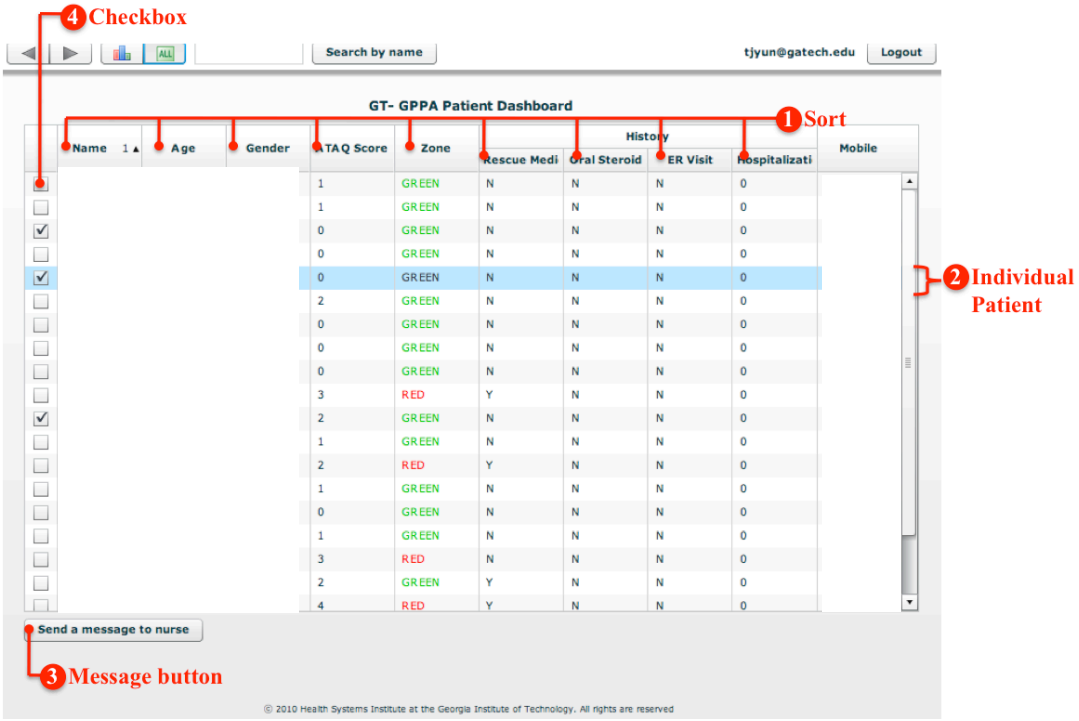
1. Sort

By clicking one of the titles in each column, you can sort patient information. For example, if you click "Name" the patient list will be presented in alphabetical order. If you click "Zone", patients will be organized by their current zone status (e.g., Green, Yellow, Red).

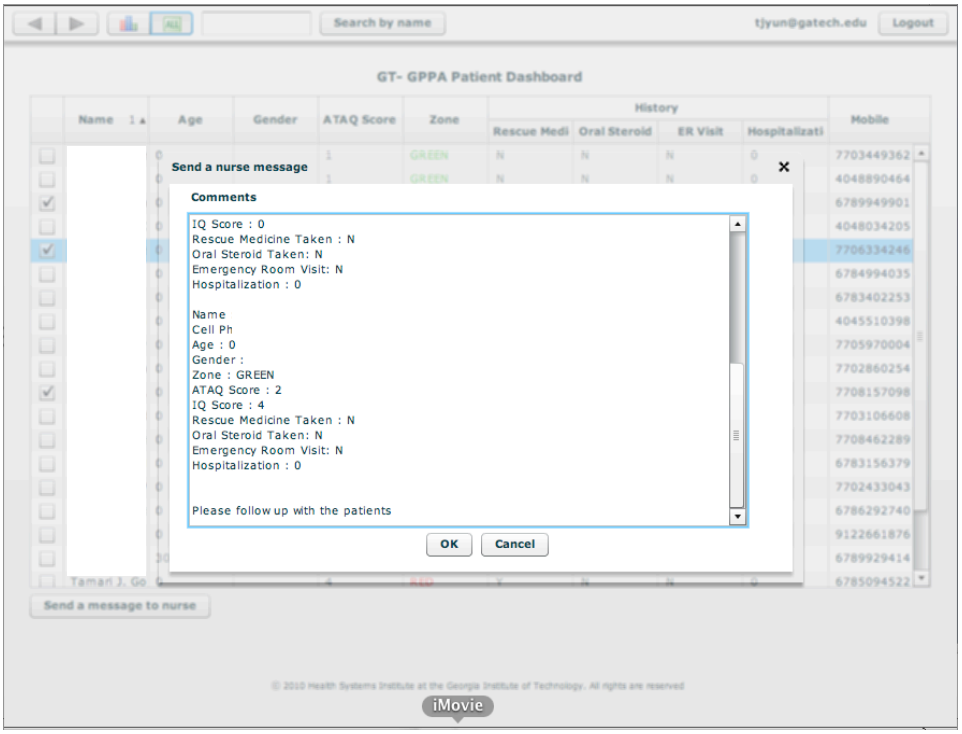
> * NOTE: "N" or "Y" in the history represents their *most recent* response for a given question (e.g., rescue medicine usage, oral steroid, ER visit, etc). For example, if a patient answered "Yes" to the rescue medicine usage question two weeks ago, "Y" is marked until the patient answers "No" for the next rescue medicine usage question. It means that if the patient answers "No" today, the status will be changed from "Y" to "N."

2. Individual patient information
If you want to see more details about one of the patients, you should click a row belonging to a patient's name (Screen 5).

3. Message button & 4. Checkbox
You can send the team a message about a given patient or group of patients you can do so by checking the box next to their name(s) (#4) and then clicking the "send the team a message" button. The list of patients you have chosen and their medical history appears on the pop-up screen (Screen 4). You can also include a personal message by typing inside the pop-up screen. When you click "OK" (Screen 4) the message is sent.



Screen 3. Table view (patient list)



Screen 4. Pop-up window for a message to nurse

D. Individual patient view

After you click one of the patients in a table view, you will go to the individual patient information screen (Screen 5). In this screen, you can see detailed information about the patient. For example, you can see this patient's zone status, the number of ER visits/Hospitalization/Rescue medicine usage, etc.

FUNCTIONS

1. Remove Alert button
By pressing the "Remove Alert" button you change your patient's status from RED to GREEN. This function allows you to be alerted to the most recent incidents. Of course, you can choose to leave the patient in the RED status if you wish.

2. ATAQ Score / IQ Score tab
By clicking each tab, you can see your patient's information. For example, if you click the "IQ Score" tab you will see the patient's IQ score. (For details regarding the items on the ATAQ and IQ data see #7 in function section below).

3. Quick timeline view
If you want to look at the ATAQ score for a specific period of time (e.g., recent 2 weeks, 4 weeks, 12 weeks from today), you can select the relevant button.

4. Calendar button
You can view the ATAQ responses for a specific period of time by clicking the calendar button (Screen 5). Once you click this button a pop-up window will appear (Screen 6). You must then select a start date and an end date on the specified calendar.

5. Plot mouse over pop-up

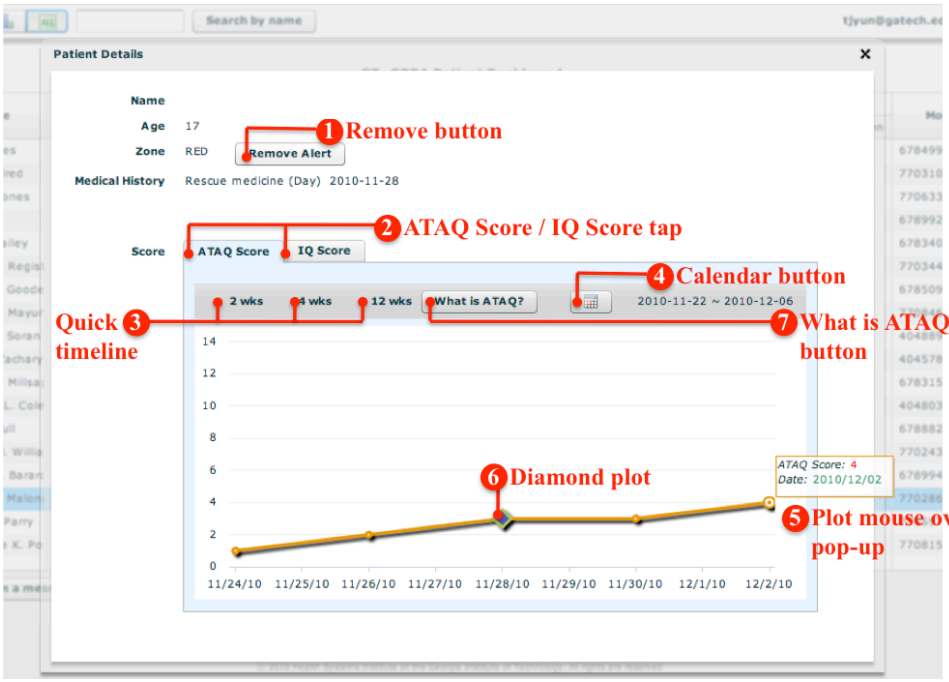
You can view the ATAQ score for a given date by hovering the mouse over that date. By clicking on the plot you will get a popup screen that provides total scores gained (X out of Y) and a list of questions the patient answered "yes/don't know" (Screen 7).

6. Diamond plot

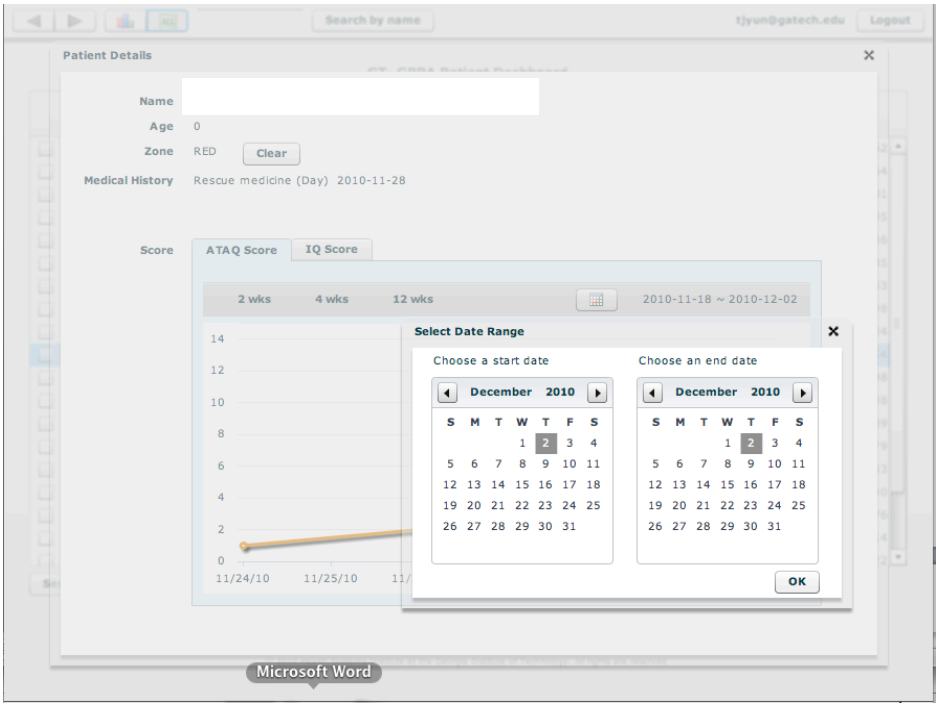
Certain questions on the ATAQ scores earn 1 or 2 points when answered in "Yes/don't know" because they are thought to indicate that the patients' asthma is not in control (see ATAQ details). These questions are demarked by a diamond on the plot.

7. What is ATAQ/IQ button

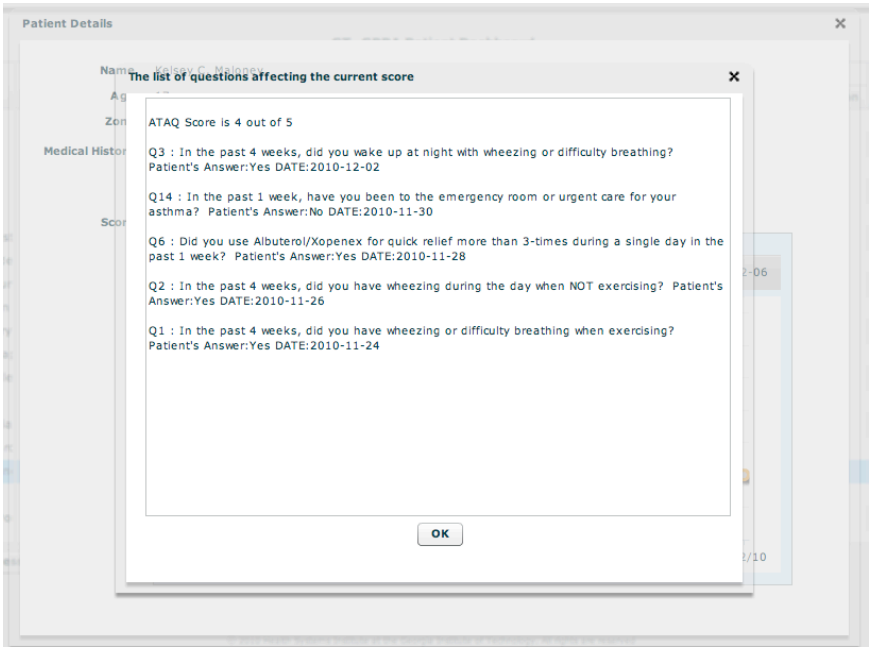
If you click this button, you can see the description about ATAQ/IQ and all ATAQ/IQ questions that patients are receiving for this study.



Screen 5. Individual patient detail view



Screen 6. Pop-up window for calendar



Screen 7. Question detail view

**** Viewing IQ score line chart***

The IQ score data chart has the same logistics as the ATAQ data chart. For example, if you want to look at the overall IQ score for a specific period of time, you can click the IQ tab (Screen 5). Likewise, when you click the plot, you will get a list of the question that the patient answered wrong in the popup screen (Screen 7). (For details regarding the items on the ATAQ and IQ data see #7 in function section above.)

APPENDIX D

SURVEYS

Subject ID: _____ Date: _____ ChildPre

This survey is for asthma research related to SMS/Text messaging. We will use this survey to understand your asthma and use of technology better. Please answer the following questions as best you can. If you need help, ask a GPPA staff member or a researcher to help you. All of your responses are confidential.

For the following sections, check or write all that apply.

1. Gender: ☐ Male ☐ Female 2. Age: _____ 3. Date of Birth: ____/____/_____ 4. Zip code: _____

5. Ethnicity/Race (Please check all that apply)

Race:	☐	**Caucasian**	☐	**African-American**	☐	**Asian**
	☐	**Native American**	☐	**Other _____**	☐	
Ethnicity:	☐	**Hispanic**	☐	**Non-Hispanic**		

6. Current grade: _____th Grade

5. What medication(s) did your doctor give you to take for your asthma? (Check all that apply *and* circle Daily, Weekly or As Needed.)

☐	**Pulmicort**	**Daily**	**Weekly**	**As Needed**
☐	**Flovent**	**Daily**	**Weekly**	**As Needed**
☐	**Qvar**	**Daily**	**Weekly**	**As Needed**
☐	**Asmanex**	**Daily**	**Weekly**	**As Needed**
☐	**Symbicort**	**Daily**	**Weekly**	**As Needed**
☐	**Advair**	**Daily**	**Weekly**	**As Needed**
☐	**Singulair**	**Daily**	**Weekly**	**As Needed**
☐	**Xolair**	**Daily**	**Weekly**	**As Needed**
☐	**Albuterol (Ventolin, ProAir)**	**Daily**	**Weekly**	**As Needed**
☐	**Maxair**	**Daily**	**Weekly**	**As Needed**
☐	**Xopenex**	**Daily**	**Weekly**	**As Needed**
☐	**Other _____**	**Daily**	**Weekly**	**As Needed**

6. Household Membership
List each person living in your home in the table below, including yourself first.

	Relationship	Sex	Age	Asthma (circle one)		Age at diagnosis
1	Me			Yes	No	
2				Yes	No	
3				Yes	No	
4				Yes	No	
5				Yes	No	
6				Yes	No	

Check or write all that apply.

7. Do you have internet access at home? ☐ Yes ☐ No

8. How many hours do you spend on the internet *per day?* _____***hrs***

9. Please indicate other places you have internet access:

☐ School ☐ Friend/Family member's house ☐ Library ☐ Other_____

10. What do you use the internet for?

☐ Homework ☐ Entertainment

☐ Internet Search ☐ Other _____ ☐ Do not use

11. What kinds of internet technologies are you using for your asthma management?

☐ Asthma games ☐ Asthma-related websites (WebMD, Air Quality Forecast)

☐ Asthma-related Internet Search ☐ Other: _____ ☐ None

12. Do you send email daily? ☐ Yes ☐ No

13. Do you send instant messages daily? ☐ Yes ☐ No

14. Do you send messages via social networks daily? (Facebook, MySpace) ☐ Yes ☐ No

15. What do you use your mobile phone for?

☐ Phone Calls ☐ Accessing the Internet ☐ Alarm/Calendar function

☐ SMS/Text ☐ None ☐ Other _____

16. Do you make calls on your cell phone daily? ☐ Yes ☐ No

17. Do you currently have an SMS text plan? ☐ Yes ☐ No

18. Do you have a data plan on your phone? ☐ Yes ☐ No

19. Do you send text messages daily? ☐ Yes ☐ No

Please select all the reasons you use SMS/Text.

☐ Chatting ☐ Homework ☐ Entertainment

☐ None ☐ Other: _____

20. **Please list the reasons you use SMS text in the order that you prefer most. *Use 1 for the reason you least prefer and 4 for the reason you most prefer*.**

_____ Chatting **_____ Homework** **_____ Entertainment**

_____ None **_____ Other: _____**

21. How many SMS/Texts do you send *and* receive monthly?

☐ **1-50** ☐ **51-150** ☐ **151-300** ☐ **301+**

22. Do you regularly check your asthma status? ☐ **Yes** ☐ **No**

23. Do you seek help with managing your asthma? ☐ **Yes** ☐ **No**

24. Have you used *SMS Text* for managing your asthma? ☐ **Yes** ☐ **No**

25. Do you think SMS text can be useful in asthma management? ☐ **Yes** ☐ **No**

26. Have you used your cell phone in any ways for your asthma management? ☐ **Yes** ☐ **No**

27. Have you shared your experience with asthma with other people? ☐ **Yes** ☐ **No**

I shared my asthma experience with: (*check all that apply*)

☐ **Teachers** ☐ **Friends**

☐ **Neighbors** ☐ **Daycare teachers**

☐ **Classmates** ☐ **School bus drivers**

Other: _____

28. Have you talked about asthma with your parent? ☐ **Yes** ☐ **No**

29. How often have you talked about asthma with your parent?

☐ **All the time** ☐ **Sometimes** ☐ **A few times** ☐ **Not at all**

30. In the past 3 months have you or a parent attended a class on asthma? If yes, please list when and where. ☐ **Yes** ☐ **No**

When? _____/_____/_____ Where? _____

31. In the past 3 months have you or a parent participated in an activity for people with asthma? (e.g., *Health fair, asthma camp or neighborhood event*) **If yes, please list when and where.** ☐ **Yes** ☐ **No**

When? _____/_____/_____ Where? _____

For the questions below, indicate how you feel by circling one of the numbers on the scale above the choices provided.

32. I feel comfortable talking to my doctor about my asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

33. I feel that I am good at managing my asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

34. I feel like I understand my asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

35. I feel confident in taking care of my asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

36. What is your asthma severity? (*circle one*)

1	2	3	4
Intermittent	Mild	Moderate	Severe

Subject ID: _____ Date: _____ ChildPOST

This survey is for asthma research related to SMS/Text messaging. We will use this survey to understand your asthma and use of technology better. Please answer the following questions as best you can. If you need help, ask a GPPA staff member or a researcher to help you. All of your responses are confidential.

For the following sections, check or write all that apply.

1. How many hours do you spend on the internet *per day?* _____ hrs

2. What do you use the internet for?

☐ Homework ☐ Entertainment

☐ Internet Search ☐ Other _____ ☐ Do not use

3. What kinds of internet technologies are you using for your asthma management?

☐ Asthma games ☐ Asthma-related websites (WebMD, Air Quality Forecast)

☐ Asthma-related Internet Search ☐ Other: _____ ☐ None

4. Do you send email daily? ☐ Yes ☐ No

5. Do you send instant messages daily? ☐ Yes ☐ No

6. Do you send messages via social networks daily? ☐ Yes ☐ No

7. What do you use your mobile phone for?

☐ Phone Calls ☐ Accessing the Internet ☐ Alarm/Calendar function

☐ SMS/Text ☐ None ☐ Other _____

8. Do you make calls on your cell phone daily? ☐ Yes ☐ No

9. Do you send text messages daily? ☐ Yes ☐ No

Please select all the reasons you use SMS/Text.

☐ Chatting ☐ Homework ☐ Entertainment

☐ None ☐ Other: _____

10. Please list the reasons you use SMS text in the order that you prefer most. Use 1 for the reason you least prefer and 4 for the reason you most prefer.

_____ Chatting _____ Homework _____ Entertainment

_____ None _____ Other: _____

11. How many SMS/Texts do you send *and* receive monthly?

☐ 1-50 ☐ 51-150 ☐ 151-300 ☐ 301+

12. Do you regularly check your asthma status? ☐ **Yes** ☐ **No**

13. Do you seek help with managing your asthma? ☐ **Yes** ☐ **No**

14. Have you used *SMS Text* for managing your asthma? ☐ **Yes** ☐ **No**

15. Do you think SMS text can be useful in asthma management? ☐ **Yes** ☐ **No**

16. Have you used your cell phone in any ways for your asthma management? ☐ **Yes** ☐ **No**

17. Have you shared your experience with asthma with other people? ☐ **Yes** ☐ **No**

I shared my asthma experience with: (*check all that apply*)

☐ **Teachers** ☐ **Friends**

☐ **Neighbors** ☐ **Daycare teachers**

☐ **Classmates** ☐ **School bus drivers**

Other: _____

18. Have you talked about asthma with your parent? ☐ **Yes** ☐ **No**

19. How often have you talked about asthma with your parent?

☐ **All the time** ☐ **Sometimes** ☐ **A few times** ☐ **Not at all**

20. Have you discussed this SMS study with your parent? ☐ **Yes** ☐ **No**

21. Did this SMS study change how often you talk to your doctor (in person, via phone or email)? ☐ **Yes** ☐ **No**

If yes, how?

_____

_____

_____

22. Did you receive calls from your doctor's office based on your response to a SMS question? ☐ **Yes** ☐ **No**

If yes, please describe what happened?

_____

_____

_____

23. In the past 3 months have you or your parent attended a class on asthma? If yes, please list when and where. ☐ **Yes** ☐ **No**

When? _____/_____/_____ Where? _____

24. In the past 3 months have you or your parent participated in an activity for people with asthma? (e.g., *Health fair, asthma camp or neighborhood event*) **If yes, please list when and where.** ☐ **Yes** ☐ **No**

When? _____/_____/_____ Where? _____

For the questions below, indicate how you feel by circling one of the numbers on the scale above the choices provided.

25. I feel comfortable talking to my doctor about my asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

26. I feel that I am good at managing my asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

27. I feel like I understand my asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

28. I feel confident in taking care of my asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

29. What is your asthma severity? (*circle one***)**

1	2	3	4
Intermittent	Mild	Moderate	Severe

-------- END --------

Subject ID: _____ Date: _____ PPRE

This survey is for asthma research related to SMS/Text messaging. We will use this survey to understand your child's asthma and use of technology better. Please answer the following questions as best you can. If you need help, ask a GPPA staff member or a researcher to help you. All of your responses are confidential.

For the following sections, check or write all that apply.

1. Are you the primary care giver for the child? ☐ **Yes** ☐ **No** **2. Zip Code _____**

3. Age _____ **4. Gender _____**

5. Ethnicity/Race (Please check all that apply)

Race:	☐	**Caucasian**	☐	**African-American**	☐	**Asian**
	☐	**Native American**	☐	**Other _____**	☐	
Ethnicity:	☐	**Hispanic**	☐	**Non-Hispanic**		

6. Education Completed (Please indicate your highest level of education.)

☐	**_____ th Grade**	☐	**College (Major: _____)**
☐	**High School/GED**	☐	**Graduate _____**
☐	**Some College (# yrs _____)**	☐	

7. Insurance Type (Please check all that apply)

☐	**Private Health Insurance**	☐	**Self Pay**
☐	**Medicaid**	☐	**Other _____**

8. What medication(s) is your child currently taking for his/her asthma? (Check all that apply *and* circle Daily, Weekly or As Needed.)

☐	**Pulmicort**	**Daily**	**Weekly**	**As Needed**
☐	**Flovent**	**Daily**	**Weekly**	**As Needed**
☐	**Qvar**	**Daily**	**Weekly**	**As Needed**
☐	**Asmanex**	**Daily**	**Weekly**	**As Needed**
☐	**Symbicort**	**Daily**	**Weekly**	**As Needed**
☐	**Advair**	**Daily**	**Weekly**	**As Needed**
☐	**Singulair**	**Daily**	**Weekly**	**As Needed**
☐	**Xolair**	**Daily**	**Weekly**	**As Needed**
☐	**Albuterol (Ventolin, ProAir)**	**Daily**	**Weekly**	**As Needed**
☐	**Maxair**	**Daily**	**Weekly**	**As Needed**
☐	**Xopenex**	**Daily**	**Weekly**	**As Needed**
☐	**Other _____**	**Daily**	**Weekly**	**As Needed**

Check or write all that apply.

9. Household Membership
List each person living in your home in the table below, including yourself first.

	Relationship	Sex	Age	Asthma (circle one)		Age at diagnosis
1	Me			Yes	No	
2				Yes	No	
3				Yes	No	
4				Yes	No	
5				Yes	No	
6				Yes	No	

Check or write all that apply.

10. Do you have Internet access at home? ☐ Yes ☐ No

11. How many hours do you spend on the internet *per day?* _____*hrs*

12. Please indicate other places you have internet access:

☐ College/ Trade School ☐ Friend/Family member's house ☐ Library ☐ Work ☐ Other _____ _____

13. What do you use the internet for?

☐ Work ☐ Online Classes ☐ Entertainment ☐ Do Not Use

☐ Internet Search ☐ Social Networking/Chat ☐ Other _____

14. What kinds of internet technologies are you using for your child's asthma management?

☐ Asthma games ☐ Asthma-related websites (WebMD, Air Quality Forecast)

☐ Asthma-related Internet Search ☐ Other: _____ ☐ None

15. Do you send email daily? ☐ Yes ☐ No

16. Do you send instant messages daily? ☐ Yes ☐ No

17. Do you send messages via social networks daily (Facebook, MySpace)? ☐ Yes ☐ No

18. What type of mobile plan does your child have?

☐ Prepaid ☐ Individual line ☐ Family Plan

☐ Contract ☐ Other _____

19. Does your child have an SMS text/data plan? ☐ Yes ☐ No

If, yes, check all that apply. ☐ SMS Text ☐ Data plan (Internet, email)

20. Which company is your child's phone plan with?

☐ Sprint ☐ AT&T ☐ T-Mobile

☐ Verizon ☐ Pay-as-you-go ☐ Other _____

21. Please select all the ways that you use your mobile phone.

☐ Phone Calls ☐ Accessing the Internet ☐ Alarm/Calendar function

☐ SMS/Text ☐ None ☐ Other _____

22. Do you make calls on your cell phone daily? ☐ Yes ☐ No

23. Do you currently have an SMS text plan? ☐ Yes ☐ No

24. Do you have a data plan on your phone? ☐ Yes ☐ No

25. Do you send text messages daily? ☐ Yes ☐ No

26. How many SMS/Texts do you send *and* receive monthly?

☐ 1-50 ☐ 51-150 ☐ 151-300 ☐ 301+

27. Please select all the reasons you use SMS/Text.

☐ Chatting ☐ Work ☐ Entertainment

☐ None ☐ Other: _____

28. Please list the reasons you use SMS text in the order that you prefer most. Use 1 for the reason you least prefer and 4 for the reason you most prefer.

_____ Chatting _____ Homework _____ Entertainment

_____ None _____ Other: _____

29. Have you used your cell phone in any way for your child's asthma management? ☐ **Yes** ☐ **No**

If yes, please describe. _____

_____

☐ **Yes** ☐ **No**

30. Do you regularly check your child's asthma status?

31. Do you seek help with managing your child's asthma? ☐ **Yes** ☐ **No**

32. Have you used *SMS Text* for managing your child's asthma? ☐ **Yes** ☐ **No**

33. Have you used your cell phone in any ways for your child's asthma management? ☐ **Yes** ☐ **No**

34. Do you think SMS text can be useful in asthma management? ☐ **Yes** ☐ **No**

35. Have you shared your experience with asthma with other people? ☐ **Yes** ☐ **No**

I shared my child's asthma experience with: (*check all that apply*)

☐ **Teachers** ☐ **Friends**

☐ **Neighbors** ☐ **Daycare teachers**

☐ **Coworkers** ☐ **School bus drivers**

Other: _____

36. Have you talked about asthma with your child? ☐ **Yes** ☐ **No**

37. How often have you talked about asthma with your child?

☐ **All the time** ☐ **Sometimes** ☐ **A few times** ☐ **Not at all**

38. In the past 3 months have you or your child attended a class on asthma? If yes, please list when and where. ☐ **Yes** ☐ **No**

When? _____/_____/_____ **Where?** _____

39. In the past 3 months have you or your child participated in an activity for people with asthma? (e.g., *Health fair, asthma camp or neighborhood event*) **If yes, please list when and where.** ☐ **Yes** ☐ **No**

When? _____/_____/_____ **Where?** _____

For the questions below, indicate how you feel by circling one of the numbers on the scale above the choices provided.

40. I feel comfortable talking to my doctor about my child's asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

41. I feel that I am good at managing my child's asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

42. I feel like I understand my child's asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

43. I feel confident in taking care of my child's asthma. (*circle one*)

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

44. What is your child's asthma severity? (*circle one*)

1	2	3	4
Intermittent	Mild	Moderate	Severe

Subject ID: _____ Date: _____ ParentPOST

This survey is for asthma research related to SMS/Text messaging. We will use this survey to understand your child's asthma and use of technology better. Please answer the following questions as best you can. If you need help, ask a GPPA staff member or a researcher to help you. All of your responses are confidential.

For the following sections, check or write all that apply.

1. How many hours do you spend on the internet *per day?* _____ hrs

2. What do you use the internet for?

☐ **Work** ☐ **Online Classes** ☐ **Entertainment** ☐ **Do Not Use**

☐ **Internet Search** ☐ **Social Networking/Chat** ☐ **Other _____**

3. What kinds of internet technologies are you using for your child's asthma management?

☐ **Asthma games** ☐ **Asthma-related websites (WebMD, Air Quality Forecast)**

☐ **Asthma-related Internet Search** ☐ **Other: _____** ☐ **None**

4. Do you send email daily? ☐ **Yes** ☐ **No**

5. Do you send instant messages daily? ☐ **Yes** ☐ **No**

6. Do you send messages via social networks daily? ☐ **Yes** ☐ **No**

7. Do you make calls on your cell phone daily? ☐ **Yes** ☐ **No**

8. Do you have a data plan on your phone? ☐ **Yes** ☐ **No**

9. Do you send text messages daily? ☐ **Yes** ☐ **No**

Please select all the reasons you use SMS/Text.

☐ **Chatting** ☐ **Homework** ☐ **Entertainment**

☐ **None** ☐ **Other: _____**

10. Please list the reasons you use SMS text in the order that you prefer most. Use 1 for the reason you least prefer and 4 for the reason you most prefer.

_____ Chatting **_____ Homework** **_____ Entertainment**

_____ None **_____ Other: _____**

11. How many SMS/Texts do you send *and* receive monthly?

☐ **1-50** ☐ **51-150** ☐ **151-300** ☐ **301+**

12. Do you regularly check your child's asthma status? ☐ **Yes** ☐ **No**

13. Do you seek help with managing your child's asthma? ☐ **Yes** ☐ **No**

14. Have you used *SMS Text* for managing your child's asthma? ☐ **Yes** ☐ **No**

15. Have you used your cell phone in any ways for your child's asthma management? ☐ **Yes** ☐ **No**

16. Do you think SMS text can be useful in asthma management? ☐ **Yes** ☐ **No**

17. Have you shared your experience with asthma with other people? ☐ **Yes** ☐ **No**

I shared my asthma experience with: (*check all that apply*)

☐ **Teachers** ☐ **Friends**

☐ **Neighbors** ☐ **Daycare teachers**

☐ **Classmates** ☐ **School bus drivers**

Other: _____

18. Have you talked about asthma with your child? ☐ **Yes** ☐ **No**

19. How often have you talked about asthma with your child?

☐ **All the time** ☐ **Sometimes** ☐ **A few times** ☐ **Not at all**

20. Have you discussed this SMS study with your child? ☐ **Yes** ☐ **No**

21. Did this SMS study change how often you talk to your child's doctor (in person, via phone or email)? ☐ **Yes** ☐ **No**

If yes, how?

_____

_____

_____

22. Did you receive calls from your child's doctor's office based on your child's response to a SMS question? ☐ **Yes** ☐ **No**

If yes, please describe what happened?

_____

_____

_____

23. In the past 3 months have you or your child attended a class on asthma? If yes, please list when and where. ☐ **Yes** ☐ **No**

When? _____/_____/_____ Where? _____

24. In the past 3 months have you or your child participated in an activity for people with asthma? (e.g., *Health fair, asthma camp or neighborhood event*) **If yes, please list when and where.** ☐ **Yes** ☐ **No**

When? _____/_____/_____ Where? _____

For the questions below, indicate how you feel by circling one of the numbers on the scale above the choices provided.

25. I feel comfortable talking to my child's doctor about my child's asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

26. I feel that I am good at managing my child's asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

27. I feel like I understand my child's asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

28. I feel confident in taking care of my child's asthma. (*circle one***)**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

29. What is your child's asthma severity? (*circle one***)**

1	2	3	4
Intermittent	Mild	Moderate	Severe

-------- END --------

ID: _____ **Name Initial**: _____ **Today's Date**: _____

Part I. Physician Initial Survey

1. Which of these questionnaires are patients or caregivers required to fill out during appointments? ☐ ACT ☐ ATAQ ☐ TRACK ☐ None ☐ Other:_____

2. How often do your patients contact you between scheduled appointments?

1	2	3	4	5
Never	Once or Twice	Sometimes	Regularly	Very Often

3. How often do you initiate communication with patients between scheduled appointments?

1	2	3	4	5
Never	Once or Twice	Sometimes	Regularly	Very Often

4. How useful would a web based system for monitoring the status of your asthma patients be?

1	2	3	4	5
Extremely Useful	Very Useful	Moderately Useful	Slightly Useful	Not At All Useful

5. How do you currently find out if and when a patient has visited the emergency room due to an asthma attack episode? ☐ During the patients next visit
☐ Phone call from the hospital ☐ Phone call from the patient/caregiver
☐ Other:_____

6. How often do you use your electronic medical record at your office?

1	2	3	4	5
Never	One to Four times a Week	One or Two times a Day	More than Two times a Day	Almost Every Hours

7. How often do you use your email at your office?

1	2	3	4	5
Never	One to Four times a Week	One or Two times a Day	More than Two times a Day	Almost Every Hours

8. What are challenges in monitoring patients' asthma management?

_____

_____

_____

******* STOP HERE *******

ID: _____ Name Initial: _____ **Today's Date**: _____

Part I. Physician Final Survey

1. How often did your patients in the study contact you during the study?

1	2	3	4	5
Never	Once or Twice	Sometimes	Regularly	Very Often

2. How often did you initiate communication with patients in the study during the study?

1	2	3	4	5
Never	Once or Twice	Sometimes	Regularly	Very Often

Part II. Use of the Technology

Have you ever used the web-based dashboard? ☐ Yes ☐ No

If no, Why? _____

_____

_____

1. It was easy to use the web-based dashboard to monitor a patients' status

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

2. It was easy to understand and interpret the Zone information displayed

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3. It was easy to understand and interpret the patient asthma ATAQ information displayed

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

4. It was easy to understand and interpret the patient asthma IQ information displayed

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

5. It was easy to understand and interpret the patient categorical information (ER/Hospitalization/Rescue Medicine/Oral Steroid) displayed?

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

ID: _____ **Name Initial**: _____ **Today's Date**: _____

6. On average, how often did you review your patients' status in the dashboard?

1	2	3	4
Never	One or More times a Month	One or More times a Week	One or More times a Day

7. Were there particular patients whose status you monitored more often than others?
☐ Yes ☐ No

7-A. If yes, who are they? ☐ Patients in Green Zone ☐ Patients in Yellow Zone ☐ Patients in Red Zone ☐ Other_____

7-B. Why were these patients viewed more often?_____

_____

8. Whenever you logged on to the dashboard, how much time do you typically spend using it?

1	2	3	4	5
1 – 15 minutes	16 – 30 minutes	31 – 45 minutes	46 – 60 minutes	More than 60 minutes

9. During what time of the day did you most often log on to the physician dashboard?

1	2	3	4
Mornings	Afternoons	Evenings	Anytime (Randomly during the day)

Part II. Satisfaction

1. The use of the dashboard did not interfere with my daily activities

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

2. The use of the dashboard improved the knowledge of current patients' status

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3. I would you like to use the physician dashboard or a similar application in the future

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

ID: _____ Name Initial: _____ **Today's Date**: _____

Part III. Value of the Technology

1. The physician dashboard is useful to monitor your patients

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Part IV. Engagement and Behavior Change

1. How often did you initiate communication with a patient after an alert was received?

1	2	3	4	5
Never	Once or Twice	Sometimes	Regularly	Very Often

Part V. Others

1. Have you changed your practices as it relates to patients' asthma management after using the dashboard from our study? ☐ Yes ☐ No

   1-A. If yes, How and Why?

   _____

   _____

   _____

   1-B. If no, Why?

   _____

   _____

   _____

2. Rank the following features in using the dashboard for monitoring patients' asthma management status (1 most important – 5 least important)
   ☐ Visualization ☐ Patients Zone Information
   ☐ ATAQ score ☐ Asthma IQ score ☐ Other: _____

3. What are challenges in using the dashboard?

   _____

   _____

4. Your comments for improving the physicians' dashboard.

   _____

   _____

******* STOP HERE *******

APPENDIX E

INTERVIEW QUESTIONS

Post Interview with Caregivers

- Tell me about the goals of the study, as you understand them (the SMS study)
- How did your child manage his/her asthma after participating in the study?
- How did your child talk about his/her asthma after participating in the study?
- What do you know about the SMS questions and information?
- What did your child tell you about the SMS study?
- Tell me about a conversation with your child's doctor during your last visit, before the study.
- Tell me about a conversation with your child's doctor today.
- What are some differences between your last visit and today?
- Did you receive phone calls from your child's doctor's office based on your child's response to a SMS question? If yes, please describe what happened? ...

Post Interview with pediatric patients

- Tell me, what do you think are the goals of the SMS messages?
- How did you manage your asthma after getting the messages?
- What was it like to answer the SMS questions?

- What were some problems you experienced while using (answering) the text message service (technical or non-technical issues)?
- Are there any important asthma related questions that you think we should have asked you during the study? If yes? What?
- How would you improve (make better) the text message service?
- Tell me about a conversation with your doctor during your last visit, before the study.
- Tell me about a conversation with your doctor today.
- What are some differences between your last visit and today?
- Did you receive calls from your doctor's office based on your response to a SMS question? If yes, please describe what happened?
- Did this text message service change how often you talk to your doctor (in person, via phone or email)? If yes, how? ...

Post Interview with Doctors

- Tell me about anything that you learned about a patient in the study that you would not have known otherwise?
- How did you notice when you received an alert about a patient?
- What did you do after receiving an alert (please provide a specific example(s))?
- How did the Zones (Green, Yellow, and Red) work for you in terms of keeping you informed about a patient's status?
- After having the dashboard, how did you manage patients? Could you please give me an example?

- How did you interact with your patients after having access to the dashboard?
- How was your patients' or caregivers' in-person communication with you different due to being enrolled in the study?
- What do you want to know about your patients between visits to help you better manage their asthma?
- How would you improve the dashboard system?
- What would be the best way for you to be updated about your patients' status?
- How did using the dashboard affect your workload? ...

APPENDIX F

HOW TO CALCULATE THE "ROLLING ATAQ" SCORE

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
Q1 Answered		Q2 Answered		Q3 Answered		Q4 Answered
8	9	10	11	12	13	14
	Q5 Answered		Q6 Answered		Q7 Answered	
15	16	17	18	19	20	21
Q8 Answered		Q9 Answered		Q10 Answered		Q11 Answered
22	23	24	25	26	27	28
	Q12 Answered		Q13 Answered		Q14 Answered	
29	30	31				
Q15 Answered (Rolling Score)		Q1		Q2		Q3

Figure 30: The "rolling ATAQ" score at 29th Sunday is the summation of answers from 1st to 29th (shaded cells).

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
Q1 Answered		Q2 Answered		Q3 Answered		Q4 Answered
8	9	10	11	12	13	14
	Q5 Answered		Q6 Answered		Q7 Answered	
15	16	17	18	19	20	21
Q8 Answered		Q9 Answered		Q10 Answered		Q11 Answered
22	23	24	25	26	27	28
	Q12 Answered		Q13 Answered		Q14 Answered	
29	30	31				
Q15 Answered		Q1 Answered (Rolling Score)		Q2		Q3

Figure 31: The "rolling ATAQ" score at 31st Tuesday is the summation of answers from 3rd to 31st (shaded cells).

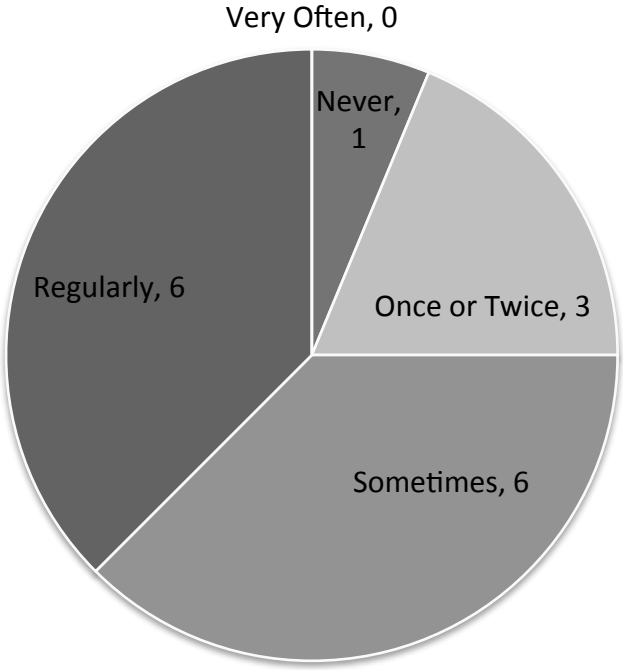
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
Q1 Answered		Q2 Answered		Q3 Answered		Q4 Answered
8	9	10	11	12	13	14
	Q5 Answered		Q6 Answered		Q7 Answered	
15	16	17	18	19	20	21
Q8 Answered		Q9 Answered		Q10 Answered		Q11 Answered
22	23	24	25	26	27	28
	Q12 Answered		Q13 Answered		Q14 Answered	
29	30	31	1	2	3	4
Q15 Answered		Q1 Answered		Q2 Not Answered		Q3 Answered (Rolling Score)

Figure 32: The "rolling ATAQ" score at 4th Sunday is the summation of answers from 5rd to 4th (shaded cells).

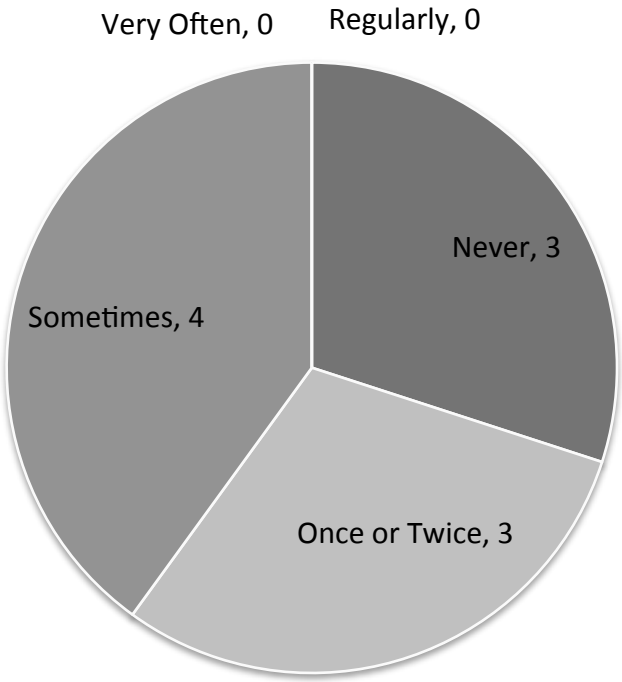
APPENDIX G

PHYSICIAN INITIAL SURVEY RESULTS

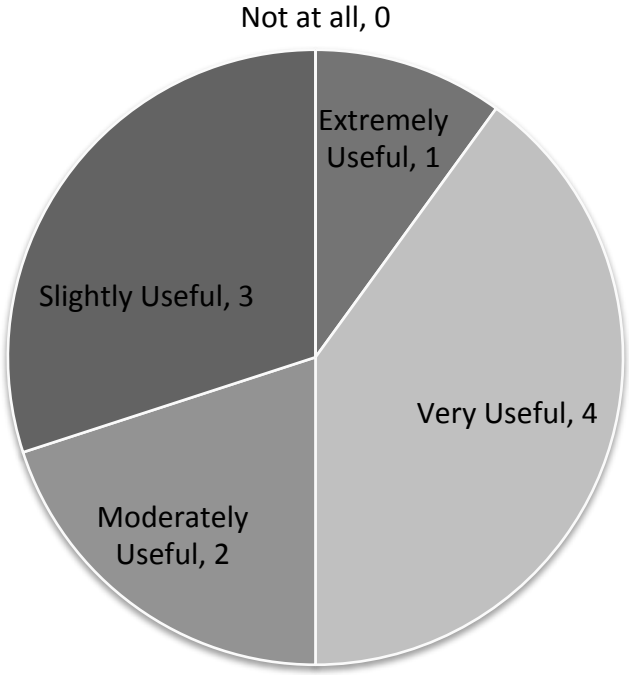
How often your patients contact you between scheduled appointemtns



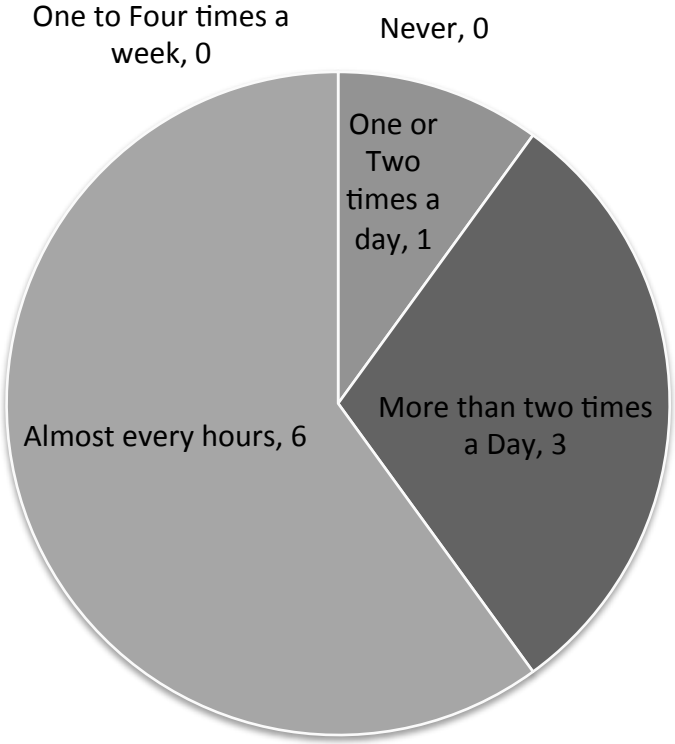
How often pulmonologist initiates communication between scheduled appointments



How a web based system would be useful for monitoring your patients



How often pulmonologist uses email at the office



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